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Presented is testimony given before the Subcommittee on the Handicapped of the Senate Committee on Human Resources regarding the Developmentally Disabled Assistance and Bill of Rights Act. Statements are included from representatives of such agencies and organizations as the National Association for Retarded Citizens, American Occupational Therapy Association, Epilepsy Foundation of America, United Cerebral Palsy Association, and the National Association of Coordinators of State Programs for the Mentally Retarded. (CL)

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OVERSIGHT ON THE DEVELOPMENTALLY DISABLED ASSISTANCE AND BILL OF RIGHTS ACT, 1977

U S DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION

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HEARING

BEFORE THE

SUBCOMMITTEE ON THE HANDICAPPED

OF THE

COMMITTEE ON HUMAN RESOURCES

UNITED STATES SENATE

NINETY-FIFTH CONGRESS

FIRST SESSION

ON

OVERSIGHT ON THE DEVELOPMENTALLY DISABLED ASSISTANCE AND BILL OF RIGHTS ACT

MARCH 31, 1977

Printed for the use of the Committee on Human Resources

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OVERSIGHT ON THE DEVELOPMENTALLY DISABLED ASSISTANCE AND BILL OF RIGHTS ACT, 1977

THURSDAY, MARCH 31, 1977

U.S. SENATE,
SUBCOMMITTEE ON THE HANDICAPPED
OF THE COMMITTEE ON HUMAN RESOURCES,
Washington, D.C.

The subcommittee met, pursuant to notice, at 9:39 a.m., in room 6202, of the Russell Office Building, Senator Jennings Randolph (Chairman of the subcommittee), presiding.

Present: Senators Randolph and Stafford.

Staff present: Pat Forsythe, professional staff member.

OPENING STATEMENT OF SENATOR JENNINGS RANDOLPH

Senator RANDOLPH. A pleasant morning to our guests.

We are appreciative of your attendance and of your concern in the matters that are being discussed by witnesses who come before our Subcommittee on the Handicapped.

This is the ninth day of hearings during the early part of the 95th Congress, indicating, I believe, the intent of our subcommittee and the Committee on Human Resources and the Senate itself, to address these important matters that are within our jurisdiction.

We are privileged this morning to have witnesses who will present their comments on the developmental disabilities programs. We will hear witnesses representing organizations as well as persons appearing as individuals. They will share with us their experiences, and they will give us their assessment of the program. This will all be helpful to us as we draft new or remedial legislation.

We feel that one of the major thrusts of this program is the development of a system for the delivery of services. As we think of the development of this system for the delivery of services to the severely handicapped, we desire to hear from the severely handicapped and the organizations representing them about what is being accomplished and whether the Federal programs are functioning properly and effectively.

Our first witness is Dr. Walter Cegelka. Doctor, if you will come up with your associate, we will ask you to identify yourself and your associate for the record.

Your complete statement or statements will be made a part of the printed published record.

STATEMENT OF WALTER J. CEGELKA, ED. D., MEMBER, NATIONAL ASSOCIATION FOR RETARDED CITIZENS, MEMBER OF GOVERNMENTAL AFFAIRS COMMITTEE, PROFESSOR, UNIVERSITY OF MISSOURI, ST. LOUIS, MO.; ACCOMPANIED BY PAUL MARCHAND, DIRECTOR OF NARC'S GOVERNMENTAL AFFAIRS OFFICE

Dr. CEGELKA. Thank you, Senator.

I am Walter Cegelka, a member of the National Association for Retarded Citizens' Governmental Affairs Committee, and chairman of the Missouri Association for Retarded Citizens' Legislative Committee.

Accompanying me today is Paul Marchand, the director of our NARC's Governmental Affairs Office.

Our organization welcomes the opportunity to discuss with you the current status of programs and services for mentally retarded citizens. This testimony will indicate to this committee the major problems confronting the field of mental retardation and how these problems reflect on the developmental disabilities program.

I am sure all of the members of this committee are well acquainted with the major developments over the past 15 years which have brought mental retardation out of the shadows.

You, Mr. Chairman, and the members of this committee must share considerable credit for focusing the attention of the Congress on this important societal concern. The National Association for Retarded Citizens certainly thanks you for your continued interest and devotion to our cause.

Given all of the new Federal benefits and society's acceptance of mental retardation, where are we now in service delivery to mentally retarded citizens?

Let's take a brief look at the current situation from the perspective of a few key programs.

EDUCATION

The right to a free, appropriate; public education has been fought for by parents of mentally retarded children for more than 25 years. Thanks to you and this committee, this great goal is close to completion, with the enactment of the Education for All Handicapped Children Act. This is especially heartwarming for the parents of severely and profoundly retarded children, who have found the doors of education closed to their children for so long. Although much needs to be done to fully implement this new law, education for all should soon be readily available.

VOCATIONAL REHABILITATION

For many years now, State vocational rehabilitation agencies have trained hundreds of thousands of mentally retarded persons for employment in outside industry or sheltered workshops. This has been a successful program. There are, however, several serious problems still confronting mentally retarded persons. The two most crucial are:

1. Recent congressionally mandated studies indicate mentally retarded persons are being seriously underserved in sheltered workshops and work activity centers.

2. Truly severely handicapped mentally retarded persons do not qualify for rehabilitation services under current limitations of the Rehabilitation Act.

Time does not permit me to go into great detail on these problems, but NARC expects to have the opportunity to discuss them when your committee considers the extension of the Rehabilitation Act. It should be made clear, however, that mentally retarded adults continue to be discriminated against in the area of rehabilitation and training.

HOUSING

In recent years, the Federal Government has probably given more publicity to its deinstitutionalization thrust than to any other mental retardation program. Unfortunately, most of this effort has been lip service. The recently completed General Accounting Office Study on "Returning the Mentally Disabled to the Community" specifies, for example, that—

> Federal officials responsible for other programs that affect deinstitutionalization generally (1) were not aware of the national goal or had not received instructions on implementation, (2) had not implemented their programs to help achieve the goal, (3) had not undertaken joint efforts directed at deinstitutionalization, or (4) had not monitored or evaluated their programs' impact on deinstitutionalization.

Deinstitutionalization is a massive undertaking. Not only must a large number of community-based residential programs be developed, but a total system of community service support programs must be set up. This effort requires a substantial Federal, State, and local financial commitment, if it is to be successful. The developmental disabilities program, for purposes of mental retardation, is the most obvious of such Federal programs. Although the Developmental Disabilities Act was never envisioned as the full solution to the problem, it is being condemned in some quarters for failing to meet these vast needs.

The General Accounting Office Study reports,

> The DD program has had a positive impact, but it has not achieved its expected potential, nor has it been able to provide all of the resources or coverage needed to achieve deinstitutionalization by itself.

The study, in reviewing the effectiveness of the State DD programs, further reports,

> . . . their success in stimulating, influencing, and coordinating other agencies' deinstitutionalization efforts was generally limited. In addition, the gaps in community-based facilities and services far exceeded the funds available.
>
> Although State developmental disabilities programs have been given broad responsibilities, their authority was not commensurate with their responsibilities. They could not require other State agencies to cooperate, nor were all other State agencies required to cooperate with State developmental disabilities councils or agencies. As a result, attempts by developmental disabilities councils or agencies to identify and resolve problems were not always successful.

NARC definitely agrees with the findings of the General Accounting Office study.

The need for community residential alternatives of many types is obvious. How to finance their development, however, is a difficult and complex undertaking. Developmental disabilities funds, limited though they are, have been effectively utilized in some States as startup or seed money, to set up such programs. In my own State of Missouri,

there are 141,000 mentally retarded persons. A conservative estimate would be that 5 percent require group home living. We currently have over 100 group homes in the State with an average of eight residents in each home for a total of about 800 group residents.

This means that in our State alone we need group home services for over 5,000 mentally retarded persons.

HUD programs are a potential source but currently present great difficulties in their use. Some States have skillfully utilized income maintenance programs, such as SSI and Social Services funds to establish group homes. However, Social Services funds are for the most part not available, thus severely limiting this resource.

Since there is no single source to finance these programs, the DD concept has great potential to bring together the varied funding sources. To do so, however, the various segments of the developmental disabilities councils, particularly the State agencies, must cooperate. The General Accounting Office Study indicates the lack of cooperation on the part of the State agencies and the lack of clout by the developmental disabilities councils has been a major deterrent to full service delivery. We hope the committee will consider this problem when you consider the extension of the developmental disabilities program.

GAPS IN SERVICE

I would now like to identify some of the major gaps in services facing mentally retarded people and their parents.

One of the most frustrating concerns confronting parents of mentally retarded persons is the difficulty in accessing services in the first place. Mentally retarded persons of all ages have many and varied needs. As you are well aware, there is no single mental retardation service delivery system. The parent of a retarded child may have to deal with more than four or five separate State agencies and an equal number of service organizations before the child reaches adulthood. At adulthood, a whole new set of agencies come into the picture. I know from many experiences that this situation poses grave dangers to the child obtaining appropriate services, the mental health of the entire family and often leads to the possibility of unwarranted institutionalization.

The role of the developmental disabilities program is most important here. Program coordination, public information, referral, and parent training are all vitally needed, high priority developmental disabilities mandates. An effective developmental disabilities program can reduce the necessity for institutionalization when these programs are implemented.

When mental retardation is diagnosed at or soon after birth, parents frequently require counseling and specialized infant stimulation for the child. Programs of this type are very scarce at the present time. Numerous studies indicate the importance of intervention at the earliest possible age. These programs are still not generally available, and there are no Federal programs which adequately address the need.

Respite care is another little known but often critical need. I personally am aware of many parents of mentally retarded children who have not been able to go on a vacation away from home for 10 or 15 years because of the problems posed by their retarded child. The bur-

dens of parenting a retarded child are heavy enough. To be forced to forgo normal recreation activities such as a night out at the movies, places unbearable extra burdens on the parents and entire family.

Senator RANDOLPH. Dr. Cegelka, if I might interrupt you for a moment with an explanation.

We have a long list of witnesses, and we are today in a situation where the Senate has determined that there will be no hearings after 11:30 this morning, because of certain legislation that is pending in the Senate. The decision was made late last evening.

That is why I suggested that you shorten your testimony and indicated that all of it will be included in the printed record. If you and the other witnesses can briefly summarize your statements for us we will be able to hear everyone in the period of time the Senate is allowing for hearings this morning. Otherwise we are going to run out of time for the witnesses who are here from the State of New Jersey, and others will be unable to be heard. I am unable to do anything about the time we have, so I hope you will be able to shorten your oral presentations.

We will also submit questions for the record rather than ask you in person today.

Thank you.

Dr. CEGELKA. The DD program has been successful in many States.

For the first time, we find that the State agencies are talking to each other and understanding each other's programs. Consumer organizations have been very successful in working together at National, State and local levels and service coordination and integration is taking place.

Finally, Mr. Chairman, and I think we would call to your attention the expiration date of the Disabilities Act in September 1978.

The National Association for Retarded Citizens is prepared to assist you and your staff in any way possible to extend and revise the program as rapidly as possible. We look forward to working with you on the developmental disabilities program in the coming months.

On behalf of the many thousands of developmentally disabled mentally retarded citizens, I urge you to continue to support the DD program and on behalf of our 225,000 members, I would like to thank you for this opportunity to testify today.

Mr. Marchand and I will be pleased to try to answer any questions you might have.

Senator RANDOLPH. Well, Dr. Cegelka, we will ask one question.

I am worried about the General Accounting Office comments. There was one statement that you had in your testimony from the General Accounting Office which indicated that the DD program had a positive impact, but it had not achieved its expected potential.

Now, should this potential already have been reached?

Dr. CEGELKA. Well, I think I would respond to that by saying that there were some difficulties in starting, delays——

Senator RANDOLPH. Delays?

Dr. CEGELKA. Yes.

That did not allow this type of ——

Senator RANDOLPH. Was that because of funding or staffing, or both?

Dr. CEGELKA. I would say to both, but particularly the delay in issuing regulations so that the States, consumer agencies, and others could understand what the rules of the game were. In addition, the developmental disabilities concept is a remarkably innovative one that requires a few years before State agencies, provider organizations, and consumer groups began to fully understand the act's intent and began feeling comfortable with the process.

Senator RANDOLPH. Thank you.

We will go into these matters.

You have said that in your opinion there is a serious gap in the lack of services to young mentally retarded children, and their families.

We have had witnesses testify before our subcommittee on the need for a comprehensive child center program.

Would such a program help to solve the problem? Would you care to comment on this?

Dr. CEGELKA. Well, there is a great need for infant stimulation and early childhood programs at the local level.

I think the real need would be in direct services to the family in the immediate local areas.

Senator RANDOLPH. I do not mean one center.

Dr. CEGELKA. Oh, I thought you meant just the national center.

Senator RANDOLPH. No, I meant a program of centers.

Dr. CEGELKA. I think that would be of tremendous assistance.

Senator RANDOLPH. You were speaking of the HUD programs, the community residential alternatives and the difficulties sometimes in the use of these alternatives.

Can you give a quick comment as to what one or two of those difficulties are?

Dr. CEGELKA. I think I would yield to Mr. Marchand, if I might.

Senator RANDOLPH. Mr. Marchand, would you respond?

Mr. MARCHAND. It is difficult to give a quick answer.

There are a batch of problems with the programs.

Senator RANDOLPH. You will expand on that answer in writing?

Mr. MARCHAND. I sure will, yes.

I would first like to commend HUD's new Secretary, Mrs. Harris, who has been meeting with organizations for the handicapped to make the programs work better for us and we are very pleased with that.

In terms of the basic program, I think one of the major problems has been that the HUD people and the local housing people do not understand the housing needs of the handicapped.

These people historically tend to work with bricks and mortar and not with program concepts such as a group home. We, ourselves, have had to train housing officials and the HUD people in all levels of government to acquaint them with the housing needs of retarded individuals.

Second, the basic program sometimes just does not fit our needs.

For instance, in order to qualify for HUD financed construction, an organization has to have exhibited a long-standing construction history and also have to be prepared to show a solid finance capacity.

That is fine for large construction firms who are going to build huge housing projects for the elderly. However, when you are trying to build a small group home, you do not have that financial capacity and you do not have that history in construction.

Another problem is that there are very minor or apparently minor details in the HUD program that just make it impossible for us to apply.

For instance, there is a series of rules dealing with unrelated adults living together in a single unit. These rules work against the development of group homes and must be resolved by the HUD people. If those were to be resolved, we would be able to use those programs far better than we can now.

There is a lot more detail to that, though, and we will answer by letter.

Senator RANDOLPH. Yes; please give us a detailed response because it will be very helpful to us.

Dr. Cegelka and Mr. Marchand, we appreciate your testimony and your understanding of our time problem. It is not of our making.

Thank you.

[The prepared statement of Dr. Cegelka and information referred to follow:]

TESTIMONY

on the

DEVELOPMENTAL DISABILITIES PROGRAM

Respectfully Submitted

to

THE SUBCOMMITTEE ON THE HANDICAPPED

of the

COMMITTEE ON HUMAN RESOURCES

UNITED STATES SENATE

Presented by:

THE NATIONAL ASSOCIATION FOR RETARDED CITIZENS

Witness:

Walter J. Cegelka, Ed. D.

Thursday, March 31, 1977

Mr. Chairman, my name is Dr. Walter Cegelka. I am a member of the National Association for Retarded Citizens' Governmental Affairs Committee, Chairman of the Missouri Association for Retarded Citizens' Legislative Committee, and the Coordinator of Special Education at the University of Missouri - St. Louis. I have been involved in most aspects of service delivery systems for mentally retarded persons for over 15 years, both in a professional and volunteer capacity. Accompanying me today is Paul Marchand, Director of NARC's Governmental Affairs Office.

Our organization welcomes the opportunity to discuss with you the current status of programs and services for mentally retarded citizens. This testimony will indicate to this committee the major problems confronting the field of mental retardation and how these problems reflect on the Developmental Disabilities Program.

I am sure all of the members of this Committee are well acquainted with the major developments over the past 15 years to bring mental retardation out into the open. You, Mr. Chairman, and the members of this Committee must share considerable credit for focusing the attention of the Congress on this important societal concern. The National Association for Retarded Citizens certainly thanks you for your continued interest and devotion to our cause.

Given all of the new Federal benefits and society's acceptance of mental retardation, where are we now in service delivery to mentally retarded citizens? Let's take a brief look at the current situation from the perspective of a few key programs.

Education

The right to a free, appropriate, public education has been fought for by parents of mentally retarded children for more than 25 years. Thanks to you and this Committee, this great goal is close to completion, with the enactment of the Education for All Handicapped Children Act. This is especially heartwarming for the parents of severely and profoundly mentally retarded children, who have found the doors of education closed to their children for so long. Although much needs to be done to fully implement this new law, education should soon be readily available.

Vocational Rehabilitation

For many years now, state Vocational Rehabilitation Agencies have trained hundreds of thousands of mentally retarded persons for employment in outside industry or sheltered workshops. This has been a successful program. There are, however, several serious problems still confronting mentally retarded persons. The two most crucial are:

1) Recent Congressionally mandated studies indicate mentally retarded persons are being seriously underserved in sheltered workshops and work activity centers.
2) Truly severely handicapped mentally retarded persons do not qualify for rehabilitation services under current limitations of the Rehabilitation Act.

Time does not permit me to go into great detail on these two problems, but NARC expects to have the opportunity to discuss them when your Committee considers the extension of the Rehabilitation Act. It should be made clear, however, that many mentally retarded adults continue to be discriminated against in the area of rehabilitation and training.

Housing

In recent years, the Federal Government has probably given more publicity to its deinstitutionalization thrust than to any other mental retardation program. Unfortunately, most of this effort has been lip service. The recently completed General Accounting Office Study on "Returning the Mentally Disabled to the Community" specifies, for example, that

> "Federal officials responsible for other programs that affect deinstitutionalization generally (1) were not aware of the national goal or had not received instructions on implementation, (2) had not implemented their programs to help achieve the goal, (3) had not undertaken joint efforts directed at deinstitutionalization, or (4) had not monitored or evaluated their programs' impact on deinstitutionalization."

Deinstitutionalization is a massive undertaking. Not only must a large number of community-based residential programs be developed, but a total system of community service support programs must be set up. This effort requires a substantial Federal, state, and local financial commitment if it is to be successful. The Developmental Disabilities Program, for purposes of mental retardation, is the most obvious of such Federal programs. Although the Developmental Disabilities Act was never envisioned as the full solution to the problem, it is being condemned in some quarters for failing to meet these vast needs.

The General Accounting Office Study reports,

> "The DD program has had a positive impact, but it has not achieved its expected potential, nor has it been able to provide all of the resources or coverage needed to achieve deinstitutionalization by itself."

The Study, in reviewing the effectiveness of the state DD programs further reports,

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> Although state developmental disabilities programs have been given broad responsibilities, their authority was not commensurate with their responsibilities. They could not require other state agencies to cooperate, nor were all other state agencies required to cooperate with State Developmental Disabilities Councils or agencies. As a result, attempts by developmental disabilities councils or agencies to identify and resolve problems were not always successful."

NARC definitely agrees with the findings of the General Accounting Office study.

The need for community residential alternatives of many types is obvious. How to finance their development, however, is a difficult and complex undertaking. Developmental Disabilities funds, limited though they are, have been effectively utilized in some states as start-up or seed money, to set up such programs. HUD programs are a potential source but currently present great difficulties in their use. Some states have skillfully utilized income maintenance programs, such as SSI and Social Services funds to establish group homes. However, Social Services funds are for the most part not available, thus severely limiting this resource.

Since there is no single source to finance these programs, the DD concept has great potential to bring together the varied funding sources. To do so, however, the various segments of the DD Councils, particularly the state agencies, must cooperate. The General Accounting Office Study indicates the lack of cooperation on the part of the state agencies and the lack of clout by the Developmental Disabilities Councils has been a major deterrent to full service delivery. We hope the Committee will consider this problem when you consider the extension of the DD program.

Gaps in Service

I would now like to identify some of the major gaps in services facing mentally retarded people and their parents. One of the most frustrating concerns confronting parents of mentally retarded persons is the difficulty in accessing services in the first place. Mentally retarded persons of all ages have many and varied needs. As you are well aware, there is no single mental retardation service delivery system. The parent of a moderately retarded child may have to deal with more than four or five separate state agencies and an equal number of service organizations before the child reaches adulthood. At adulthood, a whole new set of agencies come into the picture. I know from many experiences that this situation poses grave dangers to the child obtaining appropriate services, the mental health of the entire family and the possibility of unwarranted institutionalization.

The role of the DD program is most important here. Program coordination, public information, referral and parent training are all vitally needed, high priority DD mandates. An effective DD program can reduce the necessity for institutionalization with only these programs.

When mental retardation is diagnosed at or soon after birth, parents frequently require counseling and specialized infant stimulation for the child. Programs of this type are very scarce at the present time. Numerous studies indicate the importance of intervention at the earliest possible age. These programs are still not generally available, and there are no Federal programs which adequately address the need.

91-852 O - 77 - 2

Respite care is another little known but often critical need. I personally am aware of many parents of mentally retarded children who have not been able to go on a vacation away from home for ten or fifteen years because of the problems posed by their retarded child. The burdens of parenting a retarded child are heavy enough. To be forced to forego normal recreation activities such as a night out at the movies, dinner or a ball game places unbearable extra burdens on the parents and entire family.

Respite care can take many forms. Specially trained sitters, overnight and week-end residential care, as well as one week to one month short term residential care are all needed. Again, there is no Federal program to assist the majority of parents of mentally retarded citizens in this area of need.

Another major gap in service is transportation. Think of the problems encountered when the retarded person requires transportation everywhere he or she needs to go. School, sheltered workshop, recreation, medical care, and shopping are examples. This may not sound so bad, except that this may be a lifetime activity, with no relief in sight for the parent. Again, no basic Federal program solves this never-ending problem.

As I stated earlier, perhaps the major, most glaring lack of service is the ongoing training and day activity needs of severely retarded adults. Once the public school's responsibility has ceased, severely retarded adults (if they were educated at all), have few options. Some are evaluated by Vocational Rehabilitation agencies, but almost all are rejected for V.R. services due to their lack of

employment potential. The more fortunate ones end up in work activity centers and day training centers. However, with little or no Federal financial base for these programs, the programs do not approach meeting the need. The DD program has attempted to fill this gap in some states, but limited resources prevent most severely retarded adults from participating in daily activity programs.

Interdisciplinary Services

Since there is a need for such diverse services, parents of mentally retarded persons frequently come into contact with various professional disciplines. Examples are special educators, rehabilitation counselors, physicians, therapists, and social workers. So many times, these professionals act independently, without regard to the need of the mentally retarded person in other areas. Interdisciplinary approaches to service are many times essential to appropriately train a mentally retarded persons. The DD Act finances the major interdisciplinary training program for professionals in the DD field. This effort must be expanded so that a greater number of professionals receive this training. The National Association for Retarded Citizens supports the University Affiliated Facilities program to the fullest.

Developmental Disabilities Program

At various times during our testimony, the terms coordination and cooperation are mentioned. NARC believes them to be the essence of the DD state program. DD Councils, charged with important responsibilities with little authority, have been most successful where the members have worked in a spirit of harmony

and common interest. Many of the frustrations articulated by the developmental disabilities field reflect ineffective, non-cooperative Councils. State Council efforts continue to be hamstrung by (A) the sheer complexity of all the programs requiring coordination; (B) some basic resistance to coordinated planning by certain state agencies; (C) political problems, ranging from governors to petty bickering among provider and consumer organizations, and (D) lack of increased resources.

All these problems notwithstanding, the DD Program has been remarkably successful in many states. For the first time, state agencies are talking to each other and understanding each other's programs. Consumer organizations are very successfully working together at the national, state, and local levels. Service coordination and integration is taking place. Important state-wide planning and priority-setting is now a recognized, effective tool to assist in more appropriately spending limited but valuable resources.

The National Association for Retarded Citizens strongly believes in an effective DD Program. We are extremely excited about the new Protection and Advocacy Systems soon to be established in the states. For the first time, rights will be systematically protected and programs will be effectively monitored. We eagerly await October, 1977, so that we can begin to fully assess the virtues of the varied state Protection and Advocacy Systems. There is a high expectancy that program accountability will rise due to the new systems. Program standards are expected to be more fully met. All in all, the Developmental Disabilities Protection and Advocacy System is envisioned by the NARC as a very exciting new venture.

We commend this Committee for conceiving the concept.

Finally, Mr. Chairman, we call your attention to the expiration of the Developmental Disabilities Act in September, 1978. The National Association for Retarded Citizens is prepared to assist you and your staff in any way possible to extend and revise the program as rapidly as possible. We look forward to working with you on the DD program in the coming months. On behalf of the many thousands of developmentally disabled mentally retarded citizens, I urge you to continue to support the DD program. Thank you again for the opportunity to testify today.

national association for retarded citizens
GOVERNMENTAL AFFAIRS OFFICE
THE FEDERAL BUILDING • 1522 K STREET, N.W., SUITE 516 • WASHINGTON, D.C. 20005 • (202) 785-3388

Tony Orlando
National Honorary Chairman

Frank Menolascino, M.D.
President

Philip Roos, Ph.D.
Executive Director

June 8, 1977

The Honorable Jennings Randolph
U.S. Senate Committee on Human
Resources
Subcommittee on the Handicapped
Washington, D. C. 20510

Dear Chairman Randolph:

Thank you for the opportunity to respond to your questions concerning the testimony presented by Dr. Walter Cegelka of our organization on the Developmentally Disabled Assistance and Bill of Rights Act.

Enclosed are our answers to the four questions you posed. We hope this information is helpful to your Subcommittee.

Sincerely yours,

Paul G. Marchand

Paul A. Marchand,
Director
Governmental Affairs Office

PAM:SF
Enclosures
cc: Dr. Walter Cegelka

NATIONAL ASSOCIATION FOR RETARDED CITIZENS

RESPONSES TO QUESTIONS FROM SENATE SUBCOMMITTEE ON THE HANDICAPPED

1. You state that HUD programs are a potential source for community residential alternatives, but that the HUD programs currently present great difficulties in their use. Can you expand?

It is NARC's view that the various programs operated by the Department of Housing and Urban Development represent a largely untapped resource for developing community-based residential programs for developmentally disabled persons.

New Initiatives: We are, however, pleased to report that the Secretary of HUD, Patricia Roberts Harris, has recently taken a number of significant steps towards more fully realizing the promises of the Housing and Community Development Act of 1974 for disabled Americans. At a press conference at the White House Conference on Handicapped Individuals, Secretary Harris announced the following:

- the creation of a new Office of Independent Living within the Office of the Assistant Secretary for Housing, thereby separating for the first time the concerns of handicapped persons from those of the elderly.

- revision of the Section 8 Housing Assistance Payments program so that it can be used as an effective rent subsidy resource in group homes, sheltered apartments, and other community residential settings for mentally retarded and other handicapped people.

- a goal that 5 percent of all new family housing units constructed under both the public housing program and the Section 8 Housing Assistance Payments program will be designed for use by disabled persons.

A copy of Secretary Harris's press release is attached for your information.

Many problems remain, nevertheless.

Section 202 Loan Program: This program is designed to provide low interest loans to non-profit sponsors of housing projects for elderly or handicapped persons. Unfortunately, the selection criteria utilized by HUD in awarding Section 202 loans tended to screen out grass roots organizations interested in developing small group housing for mentally retarded and other developmentally disabled persons. HUD's selection criteria emphasized experience in construction and managing housing projects and capital reserves. Since the development of group homes is a relatively new movement and since most sponsors of such programs are non-profit community groups, they tend not to have the kinds of capital and construction experience required by Section 202.

Through the CCDD Task Force on Housing, NARC has supplied HUD with alternative criteria more appropriate to housing sponsors for projects for developmentally disabled persons, and we are hopeful that HUD will now look with more interest on these criteria.

A related problem with the Section 202 program is the absence of specific programmatic criteria in selecting sponsors. As a result, a number of sponsors proposing to build large, non-normalizing housing projects have been awarded Section 202 grants.

This problem could be partially resolved if the Department of HUD effectively implemented the requirement in the 1974 Housing and Community Development Act that:

> "In every state where a project to be assisted under this part is planned, the State Developmental Disability Council shall be given the opportunity by the Secretary for prior review and written comment concerning the need for and appropriateness of the proposed project."

Unfortunately, HUD regulations have never required DD councils to be given an opportunity for prior review.

Housing Assistance Plans: Under Title I of the Housing and Community Development Act, communities receiving Community Development Block Grants are required to develop housing assistance plans which assess housing needs and establish housing goals for elderly and handicapped persons. Unfortunately, HUD has never required that this assessment separately identify housing needs and goals for disabled persons with the result that the needs of the elderly alone are addressed in most communities. We believe this problem could be resolved expediciously through regulatory change.

2. You also state that one of the service gaps is the lack of services to young mentally retarded children and their families. As you know, we had witnesses testifying on the need for comprehensive child service centers. Would such a center satisfy the need you mention?

As programs for mentally retarded and other handicapped persons continue to expand, programs geared to meet the needs of very young (birth to school age) handicapped and at-risk children are still scarce. Infant stimulation, diagnosis and treatment, parent counseling and training are just a few of the many services that should be available at the earliest possible time in a child's life.

The testimony of Drs. Hawkins and Moriarity contains many of the program needs which we seek. Although we generally support the concepts contained in the testimony, it does not provide enough detail to warrant an endorsement by our organization. We would, however, be pleased to work with the Committee to further refine the comprehensive center approach.

3. Please provide a listing of any Federal grants your organization has and a description of the activities conducted under such grants.

NARC has the following grants and contracts with the Federal Government:

(A) A National Citizen Advocacy Model for Mentally Retarded Children
Funding Source: BEH/NIMH/RSA - HEW
Grant Period: 1972 - 1977
Current Budget: $107,260
Brief Description: This project develops printed and audio-visual materials and conducts training workshops throughout the country to develop a nationwide network of child advocacy programs. Six model citizen advocacy programs have been fully implemented through the project.

(B) Training to Facilitate the Education of the Severely Handicapped
Funding Source: BEH/HEW
Grant Period: 1975 - 1979
Current Budget: $114,000
Brief Description: This project is developing a training package which will aid in the establishment of cooperative relationships between parents and professionals in the public school education of severely and profoundly retarded students.

(C) On-The-Job Training Project
Funding Source: CETA/DOL
Contract Period: 1966 - renewed each January.
Current Budget: $931,728 (Title III); $900,000 (Title I)
Brief Description: This project places mentally retarded adults into competitive employment. This is accomplished through the development of job training and employment opportunities by field coordinators and the provision of partial reimbursement to the employer of wages paid during a training period. The project expects to place 4,158 retarded persons in jobs in 1977.

(D) Technical Assistance on the Utilization of Federal Programs to Developmental Disabilities Councils and Voluntary Agencies
Funding Source. DDO/HEW
Grant Period: 1976 - 1979
Current Budget: $254,343
Brief Description: The project is designed to assist State Developmental Disability Councils, the four major DD national voluntary organizations, and other interested parties on the state and local level to obtain better access to federal programs which can assist developmentally disabled individuals. The project is administered by NARC on behalf of United Cerebral Palsy Associations, Inc., Epilepsy Foundation of America, the National Society for Autistic Children, and NARC.

(E) Preparation and Publication of a Client-Centered Handbook on the Use of Federal Health, Education, Social and Habilitative Programs for the Developmentally Disabled.
Funding Source: DDO/HEW
Grant Period: 1976 - 1978
Current Budget: $87,120
Brief Description: This project will develop a client-centered handbook on federal resources for the professional community and pamphlets for developmentally disabled consumers. The handbook and pamphlets will facilitate the efforts of the DD Councils, voluntary organizations and consumers in accessing federal programs. The project is administered by NARC on behalf of UCP, EFA, NSAC and NARC.

(F) Project Impact
Funding Source: Office of Economic Opportunity
Grant Period: 1973 -
Current Budget: $60,000
Brief Description: This project seeks to increase minority participation in planning, developing and delivering services to low-income families of retarded persons in the southwestern region of the United States. This is accomplished through project neighborhood workers identifying and assisting low income minority families with developmentally disabled children.

4. What percentage of your organization's employees are handicapped? Please provide a breakdown of the percentage in professional positions and the percentage in clerical positions.

Total employees - 106
Total professional employees - 48
Total non-professional - 58

Total Handicapped employees - 3 (percent handicapped - 3%)
Total professional handicapped - 2 (percent handicapped - 4%)
Total non-professional handicapped - 1 (percent handicapped - 2%).

RECEIVED JUN 7 1977

HUD NEWS
U.S. DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT
WASHINGTON D.C. 20410

Phone (202) 755 5284

FOR RELEASE
Wednesday
May 25, 1977

REMARKS PREPARED FOR NEWS CONFERENCE

by

Secretary Patricia Roberts Harris

at the

White House Conference on Handicapped Individuals

Sheraton Park Hotel

Washington, D. C.

May 25, 1977

"A person who is severely impaired," Helen Keller noted, "never knows his hidden sources of strength until he is treated like a normal human being and encouraged to shape his own life."

I share with the 800 delegates to this conference, the conviction that it is time to ask every part of government to re-examine its programs and policies to determine whether they encourage the handicapped to shape their own lives and to live independently.

Dr. Henry Viscardi, Chairman of the Conference, has stated the case succinctly "the message from handicapped individuals and their families is very clear. They want action. They want follow-through. They want commitment..."

As the Secretary of the Department of Housing and Urban Development, I am here today to tell you that Americans with disabilities will get action and follow-through from HUD.

Four months ago HUD began the process of reviewing current programs and exploring new housing options for people with disabilities. A group of consumers met with me and then started to meet, on an informal basis, with HUD personnel who share their commitment to the handicapped.

That group of consumers included:

- Dr. Frank Bowe and Jan Jacobi of the American Coalition of Citizens with Disabilities;
- Ms. Eunice Fiorito from the Mayor's Office for Handicapped in New York;
- Clarke Ross from the United Cerebral Palsy Association;
- Susan Weis Manes of the National Association of Retarded Citizens;
- Cheryl Davis from the Massachusetts State Department of Community Affairs; and
- Robert Conklin of the National Association of the Physically Handicapped.

The preliminary recommendations which resulted from this interplay of ideas are being reviewed by the Department.

Today, I would like to announce some immediate decisions that were a product of this dialogue, which have been made to demonstrate HUD's commitment to Americans with disabilities.

First, effective June 6th, 1977, a new Office of Independent Living for the Disabled will be established in the Office of Housing.

This office will be headed by Dave Williamson, a career employee of the Department, and will report directly to Assistant Secretary Simons.

This will be the first time that the concerns for the disabled will be treated separately from those of the elderly.

This will be the first time that the housing concerns of the disabled will have direct attention of HUD's principal production division.

I know Dave Williamson and Larry Simons will produce more housing options for Americans with disabilities.

The new Office of Independent Living will work to make HUD more sensitive to the needs of the disabled both at the central office and in the field offices.

It will also be responsible for the activities of a departmental work-group that will draft HUD's regulatory response to the Rehabilitation Act of 1973. The Carter Administration considers these new "504" regulations to be the "Civil Rights Act" for America's disabled.

Second, HUD is establishing a goal that 5 percent of all new family housing units constructed under the Section 8 and public housing programs will be designed for use by the disabled.

The Department currently assists in the production of specially designed units for the elderly disabled under the Section 202, Section 221(d)(4) and public housing programs as well as other programs. This will be our first major commitment to the non-elderly disabled.

This new housing goal will be the first of a series of steps by HUD to provide properly designed, accessible housing for the non-elderly handicapped.

The Department will soon publish an amendment to the current Section 8 existing program. Small group homes and community residences, with shared kitchen and bathroom facilites will be an eligible and viable housing option under the amendment.

Additionally, I am working with the Counsel to the Secretary to develop other innovative approaches to the Section 8 existing program which will promote the deinstitutionalization of the mentally handicapped.

I would also like to note that we are well aware that housing without services is not adequate housing for people with disabilities. I will work with the Secretaries of Health, Education and Welfare, Labor and Transportation to develop comprehensive service programs for our housing programs.

Third, the Department will begin immediately a major effort to encourage local communities to spend a greater share of their Community Development Block Grant Funds for the elimination of architectural barriers, and the construction of rehabilitation facilities for the handicapped.

It is the Department's belief, as recently outlined by Assistant Secretary Embry, that the handicapped represent a significant portion of the population for which the Community Development program was intended.

We believe that local expenditures for the handicapped constitute an expenditure that is beneficial to low and moderate income people.

HUD is committed to an active leadership role to raise the current level of local expenditures to a level consistent with demonstrated need.

Fourth, I will continue the informal dialogue that now exists between the consumer advocates and the Department.

I will also explore the possibility of establishing a consumer advisory committee on independent living to help us make better use of our existing programs and to develop new programs so that there will be continued progress in this area.

Finally, I want all of you to know that I am committed, and the Department is committed to doing all that is in our power to eliminate the barriers which prevent Americans with disabilities from enjoying the fullest possible participation in programs, and in the activities of our society.

CONCLUSION

I have outlined today some immediate steps that the Department of Housing and Urban Development has taken on behalf of persons with disabilities.

We all recognize that these steps are just the beginning of a much larger journey that will lead to the final elimination of the barriers that imprison 10 percent of our population, this lost minority of Americans.

It is up to all of us to work to change this society designed by the able-bodied, primarily for the able-bodied -- into a society that encourages and supports satisfying life styles also for people with disabilities.

# # #

RECEIVED JUN 6 1977

HUD NEWS
U.S. DEPARTMENT OF HOUSING
AND URBAN DEVELOPMENT
WASHINGTON D.C. 20410

HUD-No. 77-154
Phone (202) 755-5284
(Farley)

FOR RELEASE AFTER:
10:00 A.M., Wednesday
May 25, 1977

HARRIS ANNOUNCES INITIATIVES
FOR THE HANDICAPPED

Patricia Roberts Harris, Secretary of Housing and Urban Development, today announced that a new Office of Independent Living for the Disabled will be established in HUD.

This new office will report directly to the Assistant Secretary for Housing and will work to make HUD more aware of the housing and environmental needs of Americans with disabilities.

At the same time, the Secretary announced several other actions that will be taken to provide more access to Federal housing programs for people with disabilities.

Included in these initiatives is Secretary Harris' decision to set the goal that 5 percent of all new family units constructed under the Section 8 and public housing programs be designed for use by the handicapped.

"This new housing goal," she said, "will mark the first of a series of steps by HUD to provide properly designed, accessible housing for the non-elderly handicapped."

Other steps will be taken to remove barriers that prevent the disabled from participating more fully in normal activities. They are:

. Local communities will be urged to spend a larger share of their community development block grant funds to eliminate architectural barriers and to build rehabilitation facilities.

. HUD will explore innovative approaches to developing alternative housing environments for the mentally disabled.

. Through the new Office of Independent Living for the Disabled, HUD will make a greater effort to sensitize the Department to the needs of the disabled.

. Under the leadership of the Office of Independent Living a work group will be set-up to draft, in cooperation with consumer and advocacy groups, HUD regulations spelling out civil rights for people with disabilities.

. The Secretary will continue working with the Ad Hoc Committee on Independent Living that was established three months ago, to work with consumers.

. She will also explore the possibility of establishing a consumer advisory committee on independent living to make better use of existing programs and to develop new programs to ensure continued progress in this area.

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Secretary Harris also noted HUD's past accomplishments in providing housing for people with disabilities under the Section 202 program.

The Secretary pledged that action will be taken to convert HUD's commitments to persons with disabilities into realities.

# # #

Senator RANDOLPH. Our next witness is Jane Salzano.

STATEMENT OF JANE SALZANO, PRESIDENT, NATIONAL SOCIETY FOR AUTISTIC CHILDREN, MARYLAND SOCIETY FOR AUTISTIC CHILDREN, SILVER SPRING, MD.

Mrs. SALZANO. Good morning.

I am Jane Salzano, president of the Maryland Society for Autistic Children.

I will skip over some of my written testimony.

I hope you got a copy of the trial residential program. It is a program of which I am familiar and I brought it along because it is an example of one project done through the State disabilities council.

Senator RANDOLPH. We do have that material. We will review it. Perhaps we might even be in touch with you.

Mrs. SALZANO. All right.

It does have the definition of autistic children.

Even more important, I think, is the reason that we have to seek a grant from the council. The grievous stress on the Federal level is to deinstitutionalization. Ironically, as the parent of an autistic child in Maryland, I could not get institutionalization if I even desired it. In Maryland, there is no State agency responsible for the autistic population.

The department of mental hygiene generally serves that segment of the population within the normal range of intelligence, manifesting a variety of emotional problems.

Pointing to the autistic person's apparently impaired level of mental functioning, this agency also excludes the autistic individual.

The department of mental retardation, on the other hand, one criteria for service is that the individual's primary handicap must be retardation.

They consider the primary handicap to be autism with retardation secondary, and therefore, they refuse to serve the autistic who is an adult.

As a parent and advocate, there are very few resources at the State level to turn to, since there would be no agency that would be held responsible for our problems. The Developmental Disabilities Act with the grant mechanism has clear value on it.

We are aware that there is a need for a wide variety of residential situations including respite care and presently the Maryland Society for Autistic Children has applied for another grant to initiate residential services for autistic citizens.

One of the things we will build on is something we learned from our original grant and that is we feel that the autistic are very well integrated with retarded population and we found that it helps the autistic.

We also found that the staff much prefer it because when you work with an autistic individual they are not going to say thank you for helping me today, whereas many of the retarded will.

On the other hand, I think it is distressing that many of the parent groups at the State level are volunteers.

We do not have the time to devote to service development and with a little bit of seed money we can get some experienced people to develop programs, residential and respite care. We cannot spend our

time going around to State agencies seeking sources, discovering all the zoning regulations that might be pertinent or even going into site acquisition.

As an advocate for autistic persons, I would press for the continuance of the Developmental Disabilities Act.

There remains an urgent need for a full spectrum of services for all developmentally disabled citizens.

I think of prime importance are grants of national significance which immediately serve developmentally disabled persons in every State.

Senator RANDOLPH. Thank you very much.

Mrs. SALZANO. Any questions?

Senator RANDOLPH. Do you know Ruth Sullivan?

Mrs. SALZANO. Oh, yes; I sure do.

Senator RANDOLPH. She has been so very active in the National Society for Autistic Children, and, she has been so very helpful to us many times. I am delighted that you, Jane, have worked with her.

Now, would you discuss with us the activities that are being carried forward at the Melwood Agricultural Training center. We understand that it is a center where an autistic person is given an opportunity to develop certain skills.

Mrs. SALZANO. They are given an opportunity there because of the program that we developed with the grants.

They were not usually accepted at the center. Although they were willing to try, they never have tried before.

Senator RANDOLPH. How long has it been in progress?

Mrs. SALZANO. This was a program we did, it was a summer program, and as a result of that they say they—you see, they had a summer farm program, during the year they have—let us see, it is a training, horticultural training center, and they say they are now willing to take autistic individuals into their horticultural experience.

Senator RANDOLPH. Horticultural or agricultural?

Mrs. SALZANO. Horticultural.

Senator RANDOLPH. Now let me ask you why the difference—horticulture, I know what it is, and we know what agriculture is. I would think there would be a mix of both of them.

Mrs. SALZANO. I think it is because of the vocation.

In that particular part of Maryland, I do not think agriculture per se is going to be successful, whereas horticulture, individuals can be trained and go out in garden shops.

Senator RANDOLPH. The students are being trained for the area in which they live?

Mrs. SALZANO. That is right. It is a training center and they live at home, and as they complete their training they can go out for employment.

Senator RANDOLPH. Do you see such a need for summer programs in other centers?

Mrs. SALZANO. Frankly, I do not see—we used it to test our hypothesis, really, because we felt that the autistic work is integrated with the retarded. We also reported living skills.

We had a recent graduate from psychology live right with the handicapped and recorded every half hour their living skills, their social

skills, et cetera, and we are really using this as an experience in developing their health care program.

Senator RANDOLPH. One further question.

What is your estimate of the number of autistic children that could be helped in the State of Maryland?

Mrs. SALZANO. Well, how would you say it could be helped?

Senator RANDOLPH. Well, I use the word——

Mrs. SALZANO. I think they all can be helped.

How many are there, is that what you are saying?

Senator RANDOLPH. Yes; certainly.

Mrs. SALZANO. The birth rate is four or five per 10,000 individuals and within that four or five in 10,000, you will find different degrees of severity, some very mildly handicapped, some severe.

When we extrapolate this we come to 1,500 in Maryland and I was sitting here trying to extrapolate that down to the States, and now I cannot.

But it is four to five. That is the agreed incidence.

Senator RANDOLPH. We thank you very much.

You have been very kind and very helpful. This is an area in which we need time to study and really learn more about it.

Mrs. SALZANO. Thank you for the opportunity.

[The prepared statement of Mrs. Salzano and material referred to follows:]

M-SAC

A CHILD IS WAITING

Maryland State Society For Autistic Children

AFFILIATED WITH THE NATIONAL SOCIETY FOR AUTISTIC CHILDREN

PLEASE REPLY TO:

14319 Briarwood Terrace
Rockville, Maryland 20853

March 31, 1977

TESTIMONY OF JANE SALZANO, PRESIDENT
MARYLAND SOCIETY FOR AUTISTIC CHILDREN

It is difficult for an advocate for autistic persons to evaluate the Developmental Disabilities Act before 1975. Autism was not included as a handicapping condition until the 1975 Amendments. Following these Amendments, a significant increase in the number of members who are advocates for autistic persons on State Developmental Disability Councils was noted.

The Developmental Disabilities Act has been responsible for partial funding of a variety of services which benefit autistic persons. Examples are:

A Center for Multiple-handicapped in Los Angeles

Project T.E.A.C.H. in South Carolina

A Summer School Program in Arizona

A Group Home for autistic teenagers in North Carolina

Several regional conferences on autism

Of particular importance are projects of national significance such as:

The Federal Programs Information and Assistance Project serving state Developmental Disabilities Councils and consumers.

The National Society for Autistic Children's Information and Advocate Service

A program, with which I am familiar, A Trial Residential Program For Autistic Adults, was made possible in 1976 by a grant through the Maryland Governor's Council on Developmental Disabilities to the Maryland Society For Autistic Children.

I have included a copy of the program report as an example of a project facilitated by the Developmental Disabilities Act. The Developmental Disability contribution was approximately $7,000.

M-SAC

A CHILD IS WAITING

Maryland State Society For Autistic Children

AFFILIATED WITH THE NATIONAL SOCIETY FOR AUTISTIC CHILDREN

PLEASE REPLY TO:

Appendix E states a working definition of autistic children and facts about autism which may be of interest to committee members.

Even more important than the report is the reason the project grant was sought.

In Maryland, no state agency is responsible for the adult autistic population.

Although the majority of these adults function at some level of retardation, one criterion for service by the Mental Retardation Administration is retardation must be the primary handicap. In the autistic person, autism is considered the primary handicap, retardation secondary.

The Department of Mental Hygiene generally serves that segment of the population, within the normal range of intelligence, manifesting a variety of emotional problems. Pointing to the autistic person's apparently impaired level of mental functioning, this agency also excludes the autistic individual.

The parent or advocate finds no service available and no agency to hold responsible for the service. Federal Developmental Disabilities funding, channeled through the state councils, is one of the few resources available to iniate any nonexisting service. Once any service is ongoing, successful and providing a necessary service, chances of a state agency assuming some responsibility are good.

The Trial Residential Program For Autistic Adults served four important purposes:

First - An excellent residential recreation program was provided for eight autistic individuals.

Second, The Maryland Society For Autistic Children gained valuable experience in iniating, staffing and administering a service program

Third - A hypothesis (autistic individuals can be successfully intergrated with retarded individuals) was tested and found valid.

Fourth - The experience is documented and available to other groups throughout the United States. The method of distribution is the National Society For Autistic Children's Information Service which is funded by Developmental Disabilities)

M-SAC

A CHILD IS WAITING

Maryland State Society For Autistic Children

AFFILIATED WITH THE NATIONAL SOCIETY FOR AUTISTIC CHILDREN

PLEASE REPLY TO:

As an advocate for autistic persons I would press for the continuance of the Developmental Disabilities Act. There remains an urgent need for a full spectrum of services for all developmentally disabled citizens.

Successful unique and innovative programs serve not only their immediate population but can be replicated throughout the fifty states.

Of prime importance are grants of national signifance which immediately serve developmentally disabled persons in every state.

TREPAA - 76

REPORT FROM THE TRIAL RESIDENTIAL PROGRAM FOR AUTISTIC ADULTS, 1976

Funded
by a grant from the
Maryland Developmental Disabilities Council

Administered
by
The Maryland Society for Autistic Children
(MSAC)

Conducted
in cooperation with
Melwood Horticultural Training Center, Inc.

Staff

Project Director, Anita King, MSW, ACSW
Chief Researcher, Deborah Beuchert, BS
Research Consultant, Jack Roth, MA, AGS

REPORT OUTLINE

I. Introduction
II. The Underlying Problem
III. Principal Findings and Recommendations
IV. Project Objectives and Approach
V. Findings
    1. Residential Experience Outcome
    2. Environmental Design Considerations (Objective (1))
        A. Physical Environment
        B. Staff Training
        C. Staff-Resident Ratio
        D. Staff-Resident Relations
        E. Appropriate Activities
    3. Assessment of Autistic Behavior Problems (Objective (2))
        A. Effect of Residential Experience on Subsequent Behavior
        B. Adjustment to Residential Experience
        C. Increase in Maladaptive Behavior
        D. Benign Nature of Maladaptive Behavior
    4. Autistic/Retarded Compatibility (Objective (3))
        A. Autistic Social Interactions
        B. Autistic/Retarded Integration
VI. Survey Findings

Appendix A - Residential Model
    1. Physical Setting
    2. Program
    3. Staff
    4. The Autistic Group
    5. The Retarded Group

Appendix B - Research Design and Results
1. Adaptive Behavior
2. Self-Care Skills
3. Maladaptive Behavior
4. Social Interaction
5. Staff Debriefing
6. Objectivity and Repeatability

Appendix C - History: MSAC - Melwood Cooperation

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1. Definition of Autistic Children
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I. INTRODUCTION

This report presents the results, the research conclusions, the survey findings, and the recommendations that evolve from the Trial Residential Program for Autistic Adults, 1976 (TREPAA - 76). TREPAA - 76 was designed to provide a one-month residential camping experience for seven young autistic adults in the company of a like number of retarded individuals. This experience provided a model for research directed toward (1) evaluation of the success of a community residential experience of this nature, involving a mixed population and the use of a staff with no prior background in dealing with autistic individuals, and (2) development of philosophy and practical recommendations for community-based residential and vocational programs that might serve autistic adults. Findings from the camping experience were supplemented by a survey involving nationwide correspondence and interviews with the few people who are presently experienced in establishing community facilities for autistic adults.

The Project was conceived by the Maryland Society for Autistic Children (MSAC) in consultation with the Melwood Horticultural Training Center, Inc., and was supported by a grant from the Maryland Developmental Disabilities Council. Both MSAC and Melwood made in-kind contributions to the project budget.

The residential camp experience was carried out during the month of August 1976 at the Melwood Farm Camp in Charles County, Maryland, and made unmodified use of the camp facilities and program that ordinarily serve retarded adults.

The Project staff consisted of Anita King, Project Director; Deborah Beuchert, Chief Researcher; Jack Roth, Research Consultant; and the Melwood Farm camp staff of Larry Hudak, Camp Director, and seven counselors. Project Bridge staff provided training for the camp staff. The Project was reviewed by a Parent/Professional Advisory Committee. Staff backgrounds and the Committee membership are presented in an appendix.

The AAMD Adaptive Behavior Scale (ABS) was modified slightly and used extensively in this project. Its application is discussed in detail in Appendix B. Copies can be obtained from the American Association on Mental Deficiency, 5201 Connecticut Avenue, N.W., Washington, D.C. 20015 or from most Special Education Departments in most school districts.

The ABS is used extensively throughout the world in evaluating retarded, emotionally maladjusted, and developmentally disabled individuals. It provides scales that rate the effectiveness of an individual in coping with the natural and social demands of his or her environment, including separate scales for Adaptive Behaviors (Part I) and Maladaptive Behaviors (Part II). Those items in Part I were used which were most relevant to the camp experience or program objectives. Part II was used in its entirety.

II. THE UNDERLYING PROBLEM

In the past, the Society for Autistic Children worked for improved educational services for autistic children and for increased public understanding of the condition. These efforts were necessary because most autistic children were forced to go to state institutions at an early age due to the lack of resources in the community. Although most of the children were "functionally retarded", they were generally excluded from community programs for retarded children due to their uniquely difficult symptoms.

Now, many communities include autistic children in special education classes, and parents are no longer routinely encouraged to abandon their autistic child to a state institution at an early age. There is an increasing number of autistic children and young adults living at home with their parents. Some of these young people are making remarkable gains and are entering the mainstream of society. Others are overcoming their most severe symptoms, but remain sufficiently handicapped that they will need special services throughout their entire lives.

In recent years, the Maryland Society for Autistic Children (MSAC) has become increasingly concerned for these young people as they become adults. Most are guaranteed a place in a special education class until the age of 21 and then have no place to go. An increasing number will be needing vocational training and a place to live in the community other than their parents' home.

The situation for autistic adults is analogous to that faced by the children several years ago. Many autistic adults operate on a "functionally retarded" level; yet due to their diagnosis or their symptoms, are frequently excluded from programs designed for adults with other developmental disabilities such as mental retardation.

Therefore, MSAC is working to insure that adequate services will become available for those individuals who were once diagnosed as autistic children. They have grown. Their symptoms have faded. Yet, it is not clear where they will fit into the spectrum of services for developmentally disabled adults. Currently, there are more questions than answers. There are many conflicting suggestions. There is great uncertainty as to specific goals and the optimal method of obtaining them. Yet there is some consensus on general priorities. These include:

1. Including those autistic adults who are not ready to join in the mainstream of society in appropriate community residential and vocational training programs.

2. Developing a broad spectrum of programs to serve both those who are mildly handicapped and the more severely involved individuals.

3. Providing training that will allow individuals to transition from more sheltered environments toward independent living as they learn new skills throughout their adult years.

4. Integrating autistic adults in residential and vocational programs with other developmentally disabled adults based on their current functional level and not on the basis of their childhood diagnosis.

There are presently no community residential facilities in Maryland geared toward the autistic adult as either the majority or minority resident. Although at times this population is accepted in day programs designed for other handicapped persons, it is generally excluded from all community residential programs. Institutions, even if considered desirable, are designed for the specific needs of

either the profoundly retarded or severely mentally ill, not the very different needs of the moderately autistic adult.

There are enough examples nationwide to demonstrate that a few autistic adults can be accommodated in small community residences, and, further, a few autistic adults have been successfully integrated with the primarily retarded populations at medium-sized private organizations such as the Devereux Foundation and Camphill.

With today's emphasis on normalization and deinstitutionalization, it is appropriate for public and private organizations to work toward more varied community programs which can meet the needs of a broader range of multihandicapped, developmentally disabled individuals including those with autistic characteristics. Because autistic adults and the retarded have historically functioned together in medium and large state institutions, and because small community residential programs now almost exclusively serve the retarded, a major question to be answered in developing new programs is whether it is desirable and feasible to design small community residences that combine retarded and autistic individuals who function at approximately the same developmental level.

The research model of this project addresses that question as a key part of providing the information needed to design successful community residential and vocational services for autistic adults.

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III. PRINCIPAL FINDINGS AND RECOMMENDATIONS

PRINCIPAL FINDINGS

The findings of the residential camp phase of this project strongly support the principle that autistic adults can function effectively in a community residential care program for developmentally disabled adults. Depending upon their level of functioning, a few might fit into programs that currently exist in Maryland; others would require placement in community homes that are more supportive and protective than most current group homes, but that can be far less restrictive than institutions. Further, it was found that combined placement of autistic individuals with the retarded is not only possible, but appeared to be beneficial to the autistics and to some retarded individuals.

The findings of the survey phase of this project indicated that the need for community residential care for autistic adults is barely beginning to be recognized nationwide; the very few programs that have recently been started resulted from the active initiation of private citizens and depend upon close cooperation of private and governmental organizations.

RECOMMENDATIONS

A. That the Maryland Society for Autistic Children immediately undertake the job of developing a Community Residential Care Program for Autistic Adults.

The success of the TREPAA-76 Project, the potential availability of funding under recent developmental disability legislation, and the existing needs all point toward immediate action. A program will not happen without vigorous private advocacy and MSAC is the only organization to perform that function.

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B. That an internal MSAC survey be performed to establish priorities for the levels of care needed most quickly. Based on this survey, a specific community residential model be selected on which to concentrate initial development efforts.
Effective development action requires a single goal. While this project supports the concept that a continuum of services is needed, dilution of effort and lack of effectiveness is likely to result unless an initial target is chosen for the full support of MSAC. Additional services should be sought subsequently.

The details of the initial choice may have to be modified as the nature of practical constraints becomes more clear, but a single objective should be retained throughout the process.

C. That MSAC and its potential supporters give consideration to the implications of the research findings of this project in designing their residential model.

Many specific recommendations and suggestions for the design of a community residence are presented in Section V highlighted by lines in both margins. Section VI describes two groups that have successfully developed similar programs in nearby states and are potential sources of consultation.

General features found to be desirable include:

- Association of the community residence with an organization that will provide vocational opportunities and training and might also share administrative responsibilities.
- Consideration of commingling autistic and retarded individuals in the program if they function on a similar developmental level. Otherwise consider commingling autistic individuals with others who have been diagnosed schizophrenic or communications-handicapped.

- Association of the community residence with a college or university that could provide consultation and training for staff, field experience for graduate students in this new area, and opportunities for on-going research and program-evaluation in order to constantly improve and refine the methodology of working with autistic adults in the community. (Preliminary interest in this area has already been expressed by a representative of one Maryland graduate school.)

IV. PROJECT OBJECTIVES AND APPROACH

The first objective of TREPAA-76 was to test the possibility of providing a successful residential experience for a group of young autistic adults in a program that included a like number of retarded individuals of similar age. Extensive behavioral data and staff comments were to be collected during this experience to affirm the potential for a mixed autistic/retarded group to function together in community residential facilities and to illuminate certain conditions that would lead to the success of such facilities.

In the Project Proposal a "successful residential experience" was defined as follows:

> Autistic persons traditionally find it difficult to adjust to change, and going to camp will involve numberous changes, including living with two totally different groups of retarded campers. This will be considered a successful experience for each camper who 'adjusts to the new environment and who functions at camp as well as he or she did at home, and who functions at home after camp as well as he or she did before camp.' This modest definition of success is determined by the fact that the camp is of brief duration and primarily recreational in its goals - with little emphasis on behavior-shaping or teaching new skills. Maintaining the baseline level of functioning is probably the most that can be expected during one month. Were we to design a long-term, permanent residence, we would aim for more training and improvement in functioning over a longer period of time.

The objectives specified in the Project Proposal that relate to the development of data pertinent to the design of a community residential facility include: (1) gathering data on environmental, staffing and program design, (2) assessment of specific problems, particularly socio-behavioral, in the autistic population which might preclude community placement, and (3) assessment of the advantages of a "mixed" population of retarded and autistic individuals versus an entirely autistic population. To support each of these objectives, data was collected, and the information developed was used to assess specific issues discussed below and to develop the Findings and Recommendations which follow.

Objective (1) Data on environmental, staffing and program design was developed through interviews with the camp staff, review of the implications of behavioral data, and subjective observation by the camp staff and researcher. Areas assessed include:

a) The nature of any special characteristics of the physical environment unique to serving the autistic, b) the relative importance of prior staff training regarding autism, c) staff-resident ratio, d) the importance of staff empathy and e) the nature of activities which most successfully retained the interest of the autistics.

Objective (2) Data on behavioral problems was developed through extensive use of formal behavior rating questionnaires filled out by parents and camp staff, interviews with the camp staff and subjective observations by the camp staff and researcher. Areas assessed included:

a) The effect of the camp experience on subsequent at-home behavior, b) autistic individuals' adjustment to the initial move to camp, to change in the retarded populations, and to changes in camp routine, c) the development of any unique behavioral problems within the autistic population and d) the significance of any maladaptive behavior changes.

Objective (3) Data on "mixed" population implications was developed through use of detailed social-interaction observations by the Researcher, interviews with the camp staff and subjective observations of the camp staff and Researcher. Areas assessed included:

a) The nature, extent and appropriateness of autistic social interactions with staff and other campers and b) the nature and degree of social interactions between the autistic and retarded groups.

The information developed in the camp environment regarding each of these areas was then used in the "Findings" section which follows to suggest guidelines for a successful community residential program that would accommodate the autistic.

V. FINDINGS

The residential camp experience provided only an imperfect model of one possible type of residential community program. Several aspects of the experience such as its limited duration, the primitive living conditions, the isolation, the lack of occupational activity, and the lack of a program directed at improving maladaptive behavior habits limit the universality of extrapolation of the research results. On the other hand, these same aspects in many instances posed more serious challenges than might be found in a well-designed residential program.

The fact that all involved -- the camp staff, the research staff, the campers (as best as could be determined) and the parents of the autistic individuals -- all enthusiastically believed that the model experience was successful, has led to the overall general finding that residential-vocational programs for autistic adults, mixed with retarded adults, are a viable concept under the right conditions. Consequently, the research results and the observations of the camp staff are used to point toward the nature of some of those conditions. Wherever this occurs, the paragraphs are marked with a line in the margins.

1. For each autistic individual who came to camp from their own home a successful residential experience was provided.

In terms of the criteria set forth, the autistic group maintained the same high level of self care behavior with which they came to camp. Upon return home, their performance was rated higher by their parents than before they left. While there was some increase in withdrawal, eccentric and resistant behavior toward the end of camp, this was deemed by the staff to be no more difficult to deal with than the behavior of the retarded groups that they had previously served.

Subjectively speaking, the staff was pleased and developed a strong interest in developing further knowledge about autism, the camp management expressed strong interest in serving a similar group next year, the campers expressed pleasure, and their parents were pleased.

2. Environmental Design Considerations (Objective (1))
Physical Environment, Staffing and Activity Findings
A. No special environmental features were identified that were specially required by this autistic population.
This finding was unanimously agreed upon by all of the camp staff despite the primitive features of summer-camp living such as single toilets and showers shared by eight people, washbasins filled by hose for washing and shaving, close and noisy communal eating quarters for 20 people, etc.

This finding is readily extendable to a community residence. There appear to be no unique requirements for privacy, convenience, or for other physical modification demanded by an autistic population. It may, however, be necessary to deal with a tendency to wander off among some less-well-functioning individuals.

B. Prior staff training and experience with autism is not required for dealing effectively with autistic adults who have a reasonably high level of functioning.
This successful residential experience was provided by a camp staff (seven counselors plus director) with absolutely no prior involvement with autism. The introduction to autistic behavior and training in dealing with it that were provided to the staff averaged less than one-half day. On the other hand, the counselors were young, energetic, caring, capable people who worked in a non-authoritarian atmosphere where problem solving was shared, and feelings and frustrations were discussed in a supportive manner. They came to care about and like the

autistic individuals and wanted to learn more about autism in general and about treatment and teaching methods they could use. The high staff morale and team spirit was no doubt essential to the success of the camp experience.

These facts indicate that in an on-going community home, the staff should have access both to group counseling that will facilitate dealing with their own feelings and frustrations, and to capable consultation regarding methods for teaching the residents and preparing them for more independent living in the community.

C. The ideal ratio of staff to residents apparently should be somewhat greater for autistics than for retarded individuals, but primarily depends on the level of functioning of the individuals irrespective of diagnosis. During this 24-hour per day camp seven counselors (five usually on duty) served a population of seven autistic plus eight or 10 retarded individuals. It was generally observed by the staff that the autistic individuals required somewhat more supervision than the retarded due to their higher energy level or, alternatively, their tendency to withdraw. Although withdrawal could make supervision easier in a custodial environment, withdrawal was not accepted at camp. If withdrawing the autistic were always encouraged to take part in group activities. It was noted, moreover, that the most attention was required by one or two individuals who tended to wander off -- a situation that might not occur in less open living conditions.

The camp staff was divided on the question of whether only four counselors -- the number normally used with 16 retarded campers -- would have been enough, given more substantial training, to deal with 16 campers -- half of whom were autistic. The majority believed that four could do the job, while others argued strongly that the workload would be too great. A contributing factor to that argument is the

fact that when four staff served the retarded population, they had four continuous days off after working for 10, whereas most of the group of seven staff had only occasional days off during the whole month.

This bears upon the observation made by others that staff involved in the demanding task of supervising emotionally disturbed individuals require regular breaks for rejuvenation if they are to maintain their effectiveness.

D. The incidence of eccentric or uncooperative behavior depended strongly on the relationship that developed between an autistic individual and the staff member who was supervising or working with him.

All behavior ratings of the autistic individuals were based on independent observations of two counselors; consistent differences over several behavior domains, were commonly found in the two ratings. While part of these differences can be due to different subjective perceptions by the two staff members or to variations in their level of contact with the individual, another part is due to the fact that the observed behavior was not the same. The personality of the counselor and the closeness he developed with the autistic camper appeared to matter significantly with regard to such items as resentment of criticism and resistance to directions. Further, much of the autistic's eccentric behavior, when it occurred, seemed to be related to their anxiety level, and staff that could provide an easy, relaxed atmosphere precipitated fewer such responses.

This observation is very significant for the insights it provides for staff selection, training and consultation for a communit[illegible] residence. The ability to relate closely with the autistics,

set clear limits in a non-threatening way, to support and encourage them, and to provide a tension-free atmosphere would appear to transcend all other qualifications.

E. Activities requiring physical involvement and/or a high level of energy intensity were better able to maintain autistic individuals' attention and interest than sedentary ones.

It was observed that the autistic group particularly liked swimming and dancing and physical sports in general so long as they could stay active. Consequently, baseball was an inappropriate sport, and while they had good skills at bowling, they did not get involved in team competition as did the retarded group and so became bored while waiting their turn. Group singing was made fun and exciting by the counselors, and consequently the autistic became intensely involved and showed special pleasure in leading the group. They showed more pleasure and interest in activities such as museum visits than did the retarded group.

On the other hand, they grew quickly bored with crafts and table games and withdrew or wandered off.

Based on this experience, appropriate tasks for a vocational adjunct to a community residence serving the autistic would appear to include physical activity with sufficient continuity and complexity or variation to maintain interest. Frequent breaks would also be useful. Repetitive tasks while seated at a table would appear to be contra-indicated by this data.

3. Assessment of Autistic Behavior Problems (Objective (3))

A. The camp residential experience led to a minor post-camp improvement in at-home behavior.

There was a small general improvement in at-home behavior of the autistic campers subsequent to the camp experience, based on data

given by the parents before camp and (one to two weeks) after return. The AAMD Adaptive Behavior Scale was used for this rating and provided the following results for scores averaged for the seven campers:

- Developmental behavior ratings (ABS Part I) which are designed to evaluate an individual's skills and habits important to personal independence in daily living increased from 76% to 77% of the potential scores. All changes were small, and five of the seven individuals showed a small improvement while two decreased less than 0.3%.

- Maladaptive behavior ratings (ABS Part II) which are designed to provide measures of maladaptive behavior and behavior disorders decreased at home from an incidence of 4.4% to 3.3% of the total-listed negative behaviors. Six of the seven individuals showed small improvement while the other (one of the two mentioned above) evidenced a minor increase of 0.7% (lower score is desirable).

These data do not conclusively demonstrate an improvement, but they support the overall subjective impressions of all parents that the camp was a positive experience and that any negative behavior patterns that may have emerged at camp were not carried back to the home.

This finding indirectly supports the concept of a residence that serves autistic adults most of the time and that also allows them to spend part time in their family homes.

B. The adjustment of the autistic individuals to the move from home to camp, to changes in camp routine and to changes in the composition of the retarded co-campers was rapid and easier than anticipated.

Autistic children are conventionally noted for their inability to adapt to change, and the likelihood that this group would have such difficulty was of major concern in the design of the project. These difficulties failed to develop as the autistic adults adjusted well to rustic living conditions, to frequent changes from announced camp routine and to a complete change in the co-camper population. These adjustments were confirmed both by obtaining the counselors' subjective views of the adjustment process and by observing trends in the adaptive behavior of the campers (as measured by self-care skills ratings from the modified AAMD Adaptive Behavior Scale).

The counselors strongly agreed with both the statement that "The autistic campers reacted well to changes in routine as compared with mentally retarded campers" and that "the autistic campers adjusted well to the changes in the retarded groups." After the new skills required by the camp conditions were quickly learned, no anomalies in self-care behavior that might indicate adjustment difficulties were observed.

Close to the end of the camp period, three of the seven autistic individuals evidenced some homesickness and anxiety about returning home -- the others appeared content to continue the experience.

This unexpectedly positive adjustment experience should be predictive of similar positive adaptation by reasonably well functioning autistic adults into a community residence and of their ability to contend with a wide variety of living conditions and variations in routine. On the other hand, the development of homesickness and anxiety by three of the campers -- the three who also had the lowest initial AAMD scores and who developed the highest increase in maladaptive behavior -- suggests that lower functioning individuals require more support or structure than was provided. It further implies that a range of community services will be required to serve autistic individuals who function at varied levels.

C. Although self-care behavior ratings (ABS Part I) improved or remained steady throughout the camp period for all autistic individuals, there was a significant rise in maladaptive behavior ratings (ABS Part II) for three of them.

The average AAMD Part II raw scores for the seven autistic individuals rated by the counselors increased from an incidence rate of 3.9% to 6.8% of the total-listed negative behaviors between the middle and the end of the residential camp experience. (Compared with the previously mentioned parental rating of 4.4% and 3.3% on the same scale before camp and after returning home. Instead of the 25% decrease in the rate of maladaptive behavior incidents after the camp as scored by the parents, there was an increase of almost 75% during the camp as scored by the staff.)

All of these ratings are subject to some question: the staff may have observed more as they got to know the individuals better. They may have grown less tolerant in their assessment of what was acceptable with increasing time, and they may have projected some of their frustrations or disappointments. Nevertheless, there was a substantial increase in maladaptive behavior for three of the autistic campers. Significantly, these three are the individuals who had the highest maladaptive behavior ratings by their parents prior to camp. These three individuals, taken as a group had incidence ratings that increased during the last half of the camp from 5.4% to 11.4%, or by more than 100%, whereas the other four together had a relatively static rating that increased from 2.7% to 3.4% of the total listed negative behaviors.

This data further supports the premise that a single-community facility design is unlikely to be appropriate for all individuals. The growth in maladaptive behavior for certain individuals may reflect the inexperience of the staff and the lack of a consistent methodological approach. While it appears that four of the campers

(those with the lowest initial incidence of maladaptive behavior) could function well with inexperienced staff, the other three would likely benefit from an environment that includes more consistent structure.

D. The so-called "Maladaptive Behavior" of all of the individuals was eccentric as opposed to destructive; they did not disrupt the camp, and the autistic behavior was not considered by the staff to present specially difficult problems.

The predominant changes were an increase in eccentric mannerisms and in uncooperative and withdrawn behavior; there were no incidents of violent, destructive or untrustworthy acts. Typical comments regarding the nature of maladaptive behavior which developed were items such as: peculiar posture, unduly upset when criticized or frustrated, negative response to orders, body and hands in motion, shy in social situations, talks and laughs inappropriately, fidgets constantly, etc. These activities were not difficult for the staff to deal with as evidenced by a poll of the counselors at the end of the camp experience that produced common agreement with the statement "The autistic don't present any special behavior problems as compared with the retarded campers."

By far the worst potential for difficulties within a community was generated by the actions of one individual who tended both to wander off and to be inappropriately dressed (although not at the same time). Even this is passive non-cooperation-as opposed to aggressive behavior against others-and involved no danger to anyone. None of the others evidenced any behavior that would be worse than unusual or puzzling to the general community. Unfortunately this strangeness could be unjustifiably frightening to some, and suggests the advisability of a low-keyed educational program in the neighborhood of any new community home.

On the other hand, camp activities included frequent trips to public facilities such as informal restaurants, beaches, bowling alleys, etc. There were no problems whatever when all the campers and the camp staff interfaced with the public as a group. And, of course, the autistic already have experience interfacing as individuals with the public in the neighborhood of their parents' homes.

These findings indicate that while the behavior of selected autistic adults exposed without restriction to the community may seem strange to the general public in some ways, there is no reason to expect serious difficulties based upon any harmful actions the autistic may take. However, some individuals will need firm restrictions on their freedom out in the community -- perhaps to the point of requiring accompaniment by staff or other residents when they leave the home or vocational program.

This suggestion of the need for different degrees of individual freedom in the community supports the concept of a continuum of services for individuals on various developmental levels.

The issue of eccentricity or strangess would argue for education and orientation of the community about planned residential facilities. However desirable as that may be, the present difficulties with locating any such facilities may make such preliminary publicity unwise.

4. Autistic/Retarded Compatibility (Objective (3))

A. The Autistic individual's social interactions were infrequent, did not increase with time as they became better acquainted with others in the program and were very brief but, nevertheless, were consistently appropriate when they occurred.

Each of the seven campers was observed for 12 one-half hour periods during different types of activities spread over the duration of the camp to determine the number, duration and appropriateness of social interactions and with whom they occurred (staff or another camper).

The autistic individuals' interactions averaged slightly over 25 per hour, more than 85% of which were with the staff and were of very brief average duration -- less than 10 seconds each -- and grew briefer as time in the camp progressed. Over 95% of all of these interactions were judged to be appropriate, that is, they were characterized as being at an acceptable social level and having a purpose such as requesting information, answering a question or constructive argumentation or conversation.

The autistic initiated very few interactions. Less than one percent of the autistic individual's time was spent interacting with other campers. Interestingly, nearly three-fourths of that time was spent with the retarded campers at their initiation as opposed to time spent interacting with other autistic individuals.

It was noted that a large portion of staff time was spent in directing the autistic, cajoling them into joining group activities and pulling them out of their reveries. Several of the retarded assisted in these tasks and took pride in seeing that the more withdrawn autistics were included in the group and that they got to the right places and stayed there.

These findings confirm general observations of autistic behavior. They initiate very few interactions -- in 34 hours of observation, there were only 25 autistic-to-autistic interactions, and these generally occurred when they were directed to perform a joint task. If

group interactions and activities are part of the program of a community residence, significant staff time will be required to initiate and direct those interactions. Many of the more socially outgoing retarded in the group will want to assist in this area and will receive satisfaction from doing it.

B. The autistic and retarded integrated well socially and presented comparable challenges to the staff.

This point is supported by the results of the staff questionnaire and by anecdotal comments from the staff. The counselors completed a questionnaire at the end of camp that included several questions pertaining to the integration and relative performance of the autistic and retarded. Possible answers were:

(Strongly agree	agree	neutral	disagree	strongly disagree)
5	3	3	2	1

Individual responses from five counselors are presented along with the average rating.

a) The autistic and retarded campers integrated well in this residential camping experience.

STRONGLY AGREE (5, 5, 5, 4, 4; average 4.6)

b) Autistic campers and retarded campers require very similar physical environments.

AGREE (5, 5, 4, 4,3; average 4.2)

c) Autistic campers reacted well to changes in routine as compared to retarded campers.

STRONGLY AGREE (5, 5, 5, 5, 3; average 4.6)

d) Autistic campers don't present any special behavior problems as compared to the retarded campers.

AGREE (5, 5, 4, 4,3; average 4.2)

e) Autistic campers require no more supervision than did retarded campers.

DISAGREE (4, 3, 2, 2, 2; average 2.6)

This answer is strongly influenced by the fact that the autistics tended to "dream off" and needed more frequent encouragement to maintain involvement in group activities.

f) Autistic campers participated as well as retarded campers in group activities.

NEUTRAL (4, 4, 3, 3, 1; average 3.0)

Since autistics are noted for withdrawal, this is a surprisingly positive response. It was expected that they would participate less well than the retarded campers in group activities. It was surprising that two staff members perceived them participating as well as and two almost as well as the retarded campers.

Specific comments from the staff relating to the mutual support between the groups were as follows:

- The autistic do not assert themselves but react appropriately to initiatives from the retarded.
- Each group uses the other to grow.
- The autistic were better behaved, but needed more encouragement to join in activities.
- The autistic rarely communicated with each other.
- The autistic and retarded interacted well.
- They mixed best at dances.
- The retarded campers helped draw the autistics into conversations and activities.
- The retarded helped assure that the autistics would come along and not withdraw and wander off.
- The autistics were more intelligent -- this was beneficial to the retarded in helping them understand problem solving.

The implications of this experience for combining autistic individuals with the retarded in a community residence are positive. The retarded can provide definite assistance in facilitating the autistics' social interactions and in helping curtail potential incidents of withdrawal and wandering off. The retarded in turn can benefit from the sense of being useful and taking leadership and may also benefit in some cases from the energy and intelligence of the autistics.

Because both groups integrate well together in the same physical facilities and because the autistics do not present aggressive behavior problems, there seems to be no special need for facilities uniquely designed for or dedicated to the autistic. Depending upon programmatic considerations, the autistic may be placed in a residential facility by themselves or located in the same facility with a group of retarded.

If autistic are commingled with retarded, the ratio of autistic to retarded appears to be flexible. The one-to-one ratio that was used successfully in the model residential experience may not be optimum -- the staff believed that a ratio of two to three retarded per autistic would probably be more satisfying for staff and residents alike in an on-going program.

These findings do not challenge the desirability of designing programs which will serve autistic adults with others who are diagnosed schizophrenic or emotionally disturbed. They do, however, suggest that placement in such programs will not be optimal for all autistic adults. Consideration of individual needs and characteristics remains the sine quo non of good program development and placement.

VI. SURVEY FINDINGS

After consulting with experts across the country and several promising literature sources, two existing programs on the East Coast were identified which may each be able to share information or experience which will assist in developing or operating successful long-term programs in Maryland. Since local circumstances differ dramatically and needs and resources are never the same in any two communities or states, the amount of really applicable information to be gained by consulting with these two groups is difficult to predict. However, it is recommended that an attempt be made to learn from their experience, and gain ideas that will support development of successful programs in Maryland.

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Director: Amy Lettick

RESIDENCE FOR FOUR ADULTS (over 21)
In operation since 1972. Private administration. Public and private funding.

In addition to its day school for children, Benhaven operates this residential unit for adults in a ranch house on a farm near New Haven. The current unit is licensed to accommodate four permanent residents and one person for brief, respite care. It is always full.

The Benhaven goal is to develop a cluster of eight houses to be built around a "New England Village Green". They will each have two wings -- one for low functioning individuals who need sheltered training and work progrms; the other for higher functioning individuals who will work in the community, but need a sheltered living situation -- either due to their own needs or the fact that they would have difficulty being socially accepted in the community and would suffer isolation if they lived on their own. The focus is on autistic and neurologically impaired adults.

The Benhaven plan proposes to serve two very different populations within the same facility in such a way that each gorup will have its own identity and will develop its own life style, yet will be available to assist or augment the other as is appropriate. The

higher functioning can gain satisfaction and grow through opportunities to fill helping or leadership roles upon occasion. The lower functioning group can benefit from the opportunity to identify with the higher functioning individuals and learn from their model.

Mrs. Lettick has directed the program since its conception and offers to provide consultation based on her past experience. She would be available to consult early in the planning stage about program design, acquiring funds, and starting a program. If the program developed in such a way that the Benhaven model would be relevant, she would arrange a visit to Benhaven, talk with the front-line staff and discuss the many small, but important, operating details that determine the outcome of an on-going program.

(2) NCSAC GROUP HOME
Greensborough, N.C.

RESIDENCE FOR FIVE AUTISTIC ADOLESCENTS
Began operation in the fall of 1976. Private administration. Public funding.

The North Carolina Society for Autistic Children operated a therapeutic camp for autistic children for five years and in 1976 expanded their program to include a group home.

This program was designed with the active cooperation of the parent group and state-employed mental health professionals. Gerald Sloan, Ph.D., who was Clinical Director of the Eastern Area Residential Treatment Home (EARTH) for children in Greenville, N.C., cooperated with the parent group in writing the application. The grant is funded with Developmental Disabilities funds.

The new home is organized as a non-profit corporation separate from the local Mental Health Center. The Board is comprised of three parents and two professionals. The admissions committee is staffed primarily by parents.

The limit of five residents was chosen both to avoid stringent state requirements for larger homes and because it was felt that five is the largest number of residents that house parents can deal with effectively. The goal of this residence does not necessarily involve returning the adolescents to their parents' homes except for visits. Long-term and/or permanent residence is anticipated.

The Triad Home For Autistic Youth located in Greensboro, North Carolina, provides long term family-like situations for five autistic and communications-handicapped persons. The Home operates year round and does not charge fees for its services. With Federal and State monies, the North Carolina Society for Autistic Children is sponsoring the Home in order to provide services to meet the special needs of autistic persons between twelve and twenty-one years of age. The North Carolina Society for Autistic Children is a state-wide, non-profit parents' organization, committed to helping autistic children and their families.

The program is designed both as a way to further the older child's education and as an alternative to inappropriate institutionalization. The staff provides or has access to education, recreation, and vocational or pre-vocational training according to each individual's need.

POPULATION WE SERVE

The Triad Home For Autistic Youth serves persons who have been labeled in a variety of ways including autistic, communications handicapped, psychotic, schizophrenic and severly emotionally disturbed. We serve children who have had life-long disorders, not primarily due to cultural inadequacy or mismanagement (as in delinquent, drug, runaway or school related problems), but those with fundamentally defective intellectual and emotional capabilities. Such children usually have severe communication defects and impaired emotional relationships with other people. Some further characteristics are:

(1) Unresponsiveness to parents
(2) Delayed, absent or peculiar speech
(3) Clinging to or avoiding people
(4) Repeating meaningless words or phrases
(5) Disliking change or excessive attachment to routines
(6) Showing unusual physical movements
(7) Overactive or withdrawn
(8) Uneveness of mental function

The child and his family must be residents of North Carolina and each child must have a family guardian willing to work with the program and able to assume responsibility for the child's financial affairs and home visits. No family will be denied service on the basis of financial considerations or income, but must be able to insure the provision of costs for diagnostic and medical services, medicine, clothing, and miscellaneous expenses from some source. Any child between twelve and twenty-one years old who is ambulatory is eligible regardless of sex or race. All diagnoses will be confirmed by the Admissions committee. The Admissions Committee is a state-wide committee appointed by the North Carolina Society for Autistic Children Board of Directors and consists of three parents and two professionals.

SERVICES OFFERED

The overriding aim of the program is to provide an integrated full-day experience that will maximize the learning and coping potential of the individual. During the week residents of the home attend a special day program established in co-operation with the Greensboro Public School System. This educational component of the Triad Home For Autistic Youth focuses on prevocational and vocational skills as well as appropriate academic goals and is carried out in a classroom setting. It is staffed by a teacher and an assistant with supportive consultive services from the Division TEACCH of the Department of Psychiatry at the UNC School of Medicine in Chapel Hill.

In the home setting, emphasis is placed on development and maintenance of appropriate self-help routines and revised as needed by trained house-parents in co-operation with the other staff and professionals. In addition to the home and educational components of the Triad Home, community resources for recreation are available for afternoons and week-ends.

The Project Director works closely with the houseparents and teachers in collaboration with Division TEACCH personnel to insure a co-ordinated program for each individual. Individual resident's programs are regularly reviewed and revised in staff meetings.

The family or guardian has direct and continuing involvement in the following ways: (1) home programs, as planned by family and staff; (2) Week-end home visits, preferably on a weekly basis, but in no case less than on a monthly basis; (3) Holiday visits, as outlined at the time of admission.

RESPITE CARE PROGRAM

The weekend respite care program provides care for two autistic persons from preschool to adulthood age when space is available. The period of stay extends from Friday evening through Sunday evening. Although no formal educational program can be planned, respite care youngsters participate in recreational activities and field trips available to the residents of the Home. Admission to the program is based on need and requests are filled on an individual basis.

ADMISSIONS PROCEDURE

Referrals may come from any source including physicians, schools, mental health centers or directly from the family. The child and family must be legal residents of the State of North Carolina. Each applicant must have a diagnosis of autism, childhood schizophrenia, severe communications handicap or some such disorder of behavior and communications of psychotic proportions to be confirmed by the Admissions Committee. The Committee meets regularly to review referral information including previous medical and psychological evaluations, social history and records of previous treatment.

Referrals should be addressed to:

Program Director
Triad Home for Autistic Youth
635 Walker Avenue
Greensboro, N. C. 27403

APPENDIX A
RESIDENTIAL MODEL

TREPPA 76 used the Melwood Farm Summer Camp as a model of a community setting that would serve both autistic and retarded adults. The reasons for choosing this camp were its general suitability, its availability and the willingness of the Melwood administrative staff to support the project. This was advantageous as the Melwood horticultural program may be appropriate as vocational training to supplement a community residence when it is established.

As is the case in many "models", the camp was not an "ideal" representation of community life. The rural setting provided little opportunity to observe the camper's responses to the challenges of an urban setting and the recreational program provided only modest data about their responses to the demands of a structured vocational program. On the other hand, there were several challenges at camp that were more demanding than one would anticipate in a permanent program; particularly the rustic living situation and the need to adjust to frequent changes in scheduled activities.

1. Physical Setting

The camp is located in Southern Maryland on the grounds of the Melwood Farm which has a program of horticultural work for developmentally disabled adults. The camp facilities and activities are totally self-contained, having little contact with the rest of the farm.

The camp facilities are more primative than would be found in a permanent residence. They consist of two small bunk-houses, a dining hall which is also used for rainy-day and evening activities, two protable toilets, a hose with hand-held basins for washing and shaving, and two showers. The setting is entirely open, with no physical constraints or boundaries to inhibit wandering off.

The camp uses its van for frequent excursions, including regular trips to swim at a college pool. There is ample area for sports, hikes, a vegetable garden, and other outdoor activities.

Although this setting is appropriate for a summer camp, it does require numerous adaptations in the life-style of each camper. The small bunk houses and limited toilet facilities demand that each individual share, cooperate and respect the needs of all the others. There is little privacy and no luxuries. It can be assumed that any permanent residence will provide more amenities and will demand less adaptability of the residents.

2. Program

The normal Melwood Farm Summer Camp program is designed to accommodate 16 retarded persons, age sixteen and above, with self-care skills and some means of communication during five eleven-day sessions from mid June through August.

In order to provide the autistic group a month-long residential experience, they were enrolled for the last two sessions with their own "mid-term" session in between. They arrived the same day as eight retarded campers, lived with them for eleven days, had the mid-term session with only the autistic group and some of the counselors, then met a new retarded group and lived with them for eleven days.

The usual camp program of activities for the retarded was not changed during these last two sessions. The only change was the addition of three counselors to the normal complement of four in order to provide for staff relief time as the camp did not close down between sessions and to allow counselors time to record data for the research aspect of TREPPA-76.

The activities program was recreational - - sports, arts and crafts, group singing, etc. Frequent excursions were made to the beach, to a pool, for bowling, with occasional restaurant meals for all the campers. The campers were responsible for cleaning and caring for their bunk, eating and play areas. They were required to set tables and clean up after meals, and care for their personal needs.

The camp program involved more intense variety (activities, schedules, personnel) than would likely occur in a community residence or in most vocational programs.

3. Staff

The camp staff and the Camp Director had no background in working with autistic individuals. The counselors were all in their twenties. Some were teachers or students with some training in special education; but none had prior experience or training in working with autistics, and a few started with no information about the condition.

The total training provided was as follows:

- Four counselors and the Camp Director received a two hour lecture on autism from the Project Director and from Ms. Holdrige, a social worker with Project Bridge -- a public school program for emotionally disturbed adolescents attended by two of the campers.

- The other three counselors spent 5 hours at Project Bridge observing classes and meeting with the Project Bridge staff at lunch and spent one night at the home of one of the campers.

- The Camp Director and one counselor met with five of the campers and their parents one evening prior to camp.

After that it was up to the camp staff to work out all situations on their own with the help they could give each other, plus any information the Researcher would provide based on the pre-camp interviews she did with the parents of the autistic group. (The researcher, as well, had no prior experience with autism.)

In short, the counselors were capable, caring people who wanted to do a good job of helping developmentally disabled people -- but they had no special interest or background in autism and received minimal on-the-job training.

The most significant factor behind their successful work seemed to be high staff morale. The Camp Director created a non-authoritarian atmosphere in which everyone shared in solving problems and could feel free to use their total creativity and imagination and work in their own style without fear of censure -- a very safe, supportive atmosphere for both staff and campers. They had good rapport with each other -- discussing problems, feelings, happy moments, frustrations, and successes. They complained to each other -- equally about autistic and retarded campers -- and they laughed a lot. There was little isolation and much communication. They maintained a strong team spirit which was no doubt essential to the successful camping experience. This was enhanced by the fact that all the camp staff lived on the grounds for the duration of camp -- in contrast to some (non-camp) residential facilities where staff are relieved of duty in eight or 12 hour shifts.

4. The Autistic Group

The campers were all children of members of MSAC. An announcement was made in the MSAC Newsletter that a grant had been obtained which would pay tuition for one month at the Melwood Farm Camp. The seven applicants were then accepted on a first-come, first-served basis. The two female and five male autistic individuals who took part in this program ranged in age from fifteen to twenty-seven years of age. All lived at home with their parents. Five are presently in public school classes for emotionally disturbed, moderately retarded or trainable retarded adolescents; one attends a private school; and the oldest works part-time in a sheltered workshop.

They have each participated in several different treatment modalities and/or a variety of special classes in public and private schools for emotionally disturbed children. Most have lived away from their family for a few years at either a private school or a state institution. Six have attended Linwood Children's Center in Ellicott City, Maryland for periods of time ranging from one to ten years.

This group is representative of many autistic children who grow into adolescence and adulthood showing moderate gains. Unlike a few autistic children who make dramatic progress, they are unlikely to join the mainstream of society and be independently self-sufficient. Yet, clearly, they will not require institutional care if alternatives are available. They appear to be relatively typical of those individuals who can benefit from small residential programs coupled with vocational training. Their experiences during the trial Residential Program went so much better than anticipated and they fit in so well with the retarded campers that it seemed appropriate to check the degree to which they had shown the severe symptoms generally associated with childhood autism.

Consequently the parents were asked to complete an additional questionnaire about the early symptoms and treatment of the campers. The response showed that these individuals had each been diagnosed as moderately to severely autistic and had severe behavior problems during at least part of their childhood.

Every individual had major impairments in communication, including but not limited to these symptoms:

2 children - non-verbal until age 6
1 child - non-verbal until 7
1 child - used only one-word answers until 6
1 child - used only one-word answers until 7
1 child - had little speech until 4, then was echolalic
1 child - lost speech at 2

Severe screaming or tantrums characterized the years of muteness or limited speech for two children; one child screamed excessively from the age of two to eight; and one from the age of five to ten.

Social interaction problems included withdrawing from interpersonal contact for many years. One child seemed deaf until four. One wandered away from home until the age of eleven, while one was persistently overly-dependent on his mother's presence. A few still remain shy in the presence of strangers.

Miscellaneous symptoms included head-banging until four, needing to be fed until five, refusing to chew until nine, finickiness about food, not being toilet trained until ten, demanding exact routines from their parents, engaging in repetitive activities, having no imaginative play.

Their ability to accommodate fairly adequately to the demands of the camp at this stage of their life appears to be a testimony to the great potential for improvement in autistic children when they are given sufficient help.

An Exception. The project planned to include one individual from a state institution. However, she participated for only four days before being returned to the institution. MSAC invited Rosewood to send an autistic girl to participate, in part to test the feasibility of bringing an individual out of a state facility and in part because there were only two other female applicants. Rosewood recommended a teenager whom they said was especially anxious to get out of her cottage as she had no family involvement -- no visits, no trips. She had been a resident since the age of seven and had one unsuccessful camp experience five years previously, but they wanted her to try again.

Unfortunately, she presented challanges at camp that simply could not be handled in that unstructured environment. She demanded attention, had violent tantrums when frustrated, was dangerous to herself and others and quickly alienated both the other campers and the staff. After only four days, it proved imperative for her to return to Rosewood in order to maintain a workable situation for the other sixteen campers.

This girl's out-going behavior, incessant demands for attention, and constant chatter were so atypical of the autistic syndrome that she raised serious questions about our wisdom in including her as an "autistic camper".

Her inability to cope with the challanges of sharing a small bunk house with seven other girls, of accommodating to the give and take of the camp, of gaining acceptance from the other campers, points to the fact that the successful campers did, indeed, deal with some very real challanges. It required voluntary cooperation from everyone in order to have a harmonious program.

Melwood has successfully included many campers from state institutions. It is simply not clear why it was not the right program for this particular girl at this particular time. Since there are so very many unknown variables in her situation, her experience has not been included in the statistics, conclusions or recommendations.

5. The Retarded Group

There were eight retarded campers during the first eleven days and ten retarded campers during the last eleven days of the residential program. They came from a wide variety of backgrounds and current living situations. Some lived with their parents, some in state institutions, some in community residential programs, and a few were enrolled in vocational training programs.

They were all capable of self-care and were generally quite self-sufficient, although they tended to be less well-coordinated than the autistics. They were all verbal although several had speech defects and a few spoke very little. Allowing for the broad variations within both groups, the retarded group was fairly comparable to the autistic group in daily functioning and self-care skills. As a group, the retarded campers were more outgoing and had more highly developed skills in the areas of social interaction, cooperation, spontaneously helping others, taking leadership or teaching roles, team play and competitive sports.

The retarded campers initiated caring relationships and emotional bonds between people while only one autistic camper displayed emotional warmth. However, they seemed to benefit from the intellectual understanding of situations, curiosity, and problem-solving abilities of the autistic campers.

APPENDIX B

RESEARCH DESIGN AND RESULTS

The primary areas of investigation relevant to the project objectives included self-care skills, social functioning and interaction, degree of integration with the camp staff and the other campers, and special behavior problems the autistic campers posed and how they were dealt with.

Data was collected prior to, during, and after the camp. Parents profiled their child's level of independence in daily living, the frequency and types of maladaptive behaviors characteristic of their child, and a brief history of the course of their child's autism. The camp staff provided input on the autistic camper's levels of basic self-care skills, and occurrence of maladaptive behaviors by both autistic and retarded campers. They also shared their thoughts, feelings, and ideas on the experience and future programs for the autistic adult. The Researcher spent every day and some nights at camp assessing self-care skills and social interaction behavior, and maintained a daily log of the events pertinent to the program objectives. Follow-up data was provided by parents about their child's readjustment to home life and his/her enjoyment of camp.

The following sections describe the data collection instruments and methodology, followed by summary compilations of the derived data. The data presented here is highly summarized for purposes of economy. Only sufficient data to support the findings is included. More detailed summaries and extensive raw-data are available from the Project Director or from MSAC.

The implications of the data are discussed in the section on Findings.

1. a. Adaptive Behavior Research Design

The American Association on Mental Deficiency (AAMD) Adaptive Behavior Scale (ABS) Part I was employed to assess the autistics' degree of independence in daily living. The ABS is used extensively throughout the world in evaluation retarded, emotionally maladjusted, and developmentally disabled individuals. It provides scales that rate the effectiveness of an individual in coping with the natural and social demands of his or her environment, including separate scales for adaptive (Part I) and maladaptive (Part II) behaviors and incorporates a number of behavioral sub-domains.

Those items and sub-domains in Part I were used which were most relevant to the camp experience or program objectives. They covered indipendent functioning, language development, numbers and time, domestic activity, self-direction, responsibility, and socialization. Other instruments such as the Progress Assessment Chart were evaluated for potential use, but the ABS was found to provide the most appropriate objective description and evaluation of the autistic camper's skills and habits in areas important to the development of personal independence in daily living.

Ratings for each autistic camper on the modified ABS Part I were taken at three different points in time.

1) Prior to camp, the researcher visited each camper's home, explained the purpose of the scale to the parents and recorded their responses for each item. This pre-camp assessment served as a baseline from which to compare self-care behavior at camp and following camp.

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2) At the end of camp, the staff rated the autistic campers on these same items. Each camper was assessed independently by two different counselors. Counselors rated same-sex campers only; assessment of skills was based on the entire camp stay.

3) One-to-two weeks after camp, parents were again asked by the Researcher to evaluate their son/daughter's behavior since returning from the residential experience. The same interviewing procedure was followed as for the pre-camp visit.

This data permitted comparisons that would illuminate any contrast in at-home adaptive behavior before and after camp and any disagreements between parent and staff ratings.

1. b. Adaptive Behavior, Results

Table 1 presents the total scores for each camper from the modified ABS Part I. Self-care skills, discussed later, is a sub-domain of this data. The individuals, as rated by their parents, are relatively well functioning in all these areas with performance ranging from over 60% to almost 90% of the maximum possible score.

The changes in ratings subsequent to the camp experience were very small, with four individuals showing a slight increase (improvement) in score and two showing a slight decrease. One rating was not obtained.

Staff ratings do not correlate well with parent data and no particular significance is attached to this. Part of the variation is due to lack of counselor opportunity to observe certain skills in the camp environment that were observed and rated by the parents.

Table 1

Summary of Modified AAMD Adaptive Behavior Scale, Part I

Adaptive Behavior Ratings*

Autistic Camper	Parent Rating		Staff Rating
	Pre-Camp	Post-Camp	End of Camp
a	193	(193)**	194.5
b	181	186	171.5
c	179	186	174.5
d	158	153	110.5
e	162	164	126.5
f	152	165	134.5
g	133	128	71
Average score for all autistics	165.4	167.8	140.4
Percent of maximum obtainable score*	76%	77%	65%

*High scores represent mastery of a higher proportion of adaptive behaviors and self-care skills.

**( ) Not rated; value assumed.

2. a. Self Care Skills, Research Design

Ratings of basic self-care skills selected from the ABS Part I were performed on an every-other-day or daily basis to document any change in behavior. Items rated included toileting, dressing and undressing, shoes on and off, showering, toothbrushing, washing, upkeep of personal belongings and bunk area, eating skills and table manners. Fifteen ratings for each camper were recorded, five during each of the two sessions, and five during the inter-term period. This break in routine was expected to be a difficult time for the autistic campers so daily ratings were scheduled during this period.

A female and a male counselor rated the female and male autistic campers respectively in the areas of toileting, dressing and undressing, shoes, and upkeep of bunk area. The other areas were assessed by the Researcher. Ratings on washing skills and toothbrushing were made at the morning wash-up. To assess use of table utensils, drinking behavior, and table manners, the campers were divided into two groups that were each rated at fifteen meals spaced evely throughout the entire month and scheduled to include an equal number of breakfasts, lunches, and dinners.

This data provides a basis to determine the rate at which the autistic individuals adapted to the new self-care skills required at camp and whether any deterioration in these skills accured over time or coincided with major changes in the environment.

2. b. Self Care Skills, Results

The autistic group displayed a high level of competence in all the rated self care skills and, although there was minor variability, the ratings were generally consistently high throughout the program.

Figure 1 displays the average total-group score for all skills on each date that self-care was rated. This method of presentation was chosen because the small variations in the high level of skills did not warrent individual comparison (87%-99% of obtainable scores).

The data is consistent with a postulated rising trend in self-care skills (Line A) as the group learns how to deal with their new environment, a minor drop (Line B) when the first group of retarded campers departed and the autistic were alone during the interim session, and a continuing increase (Line C) during the final session.

Specific skill observations are as follows:
Washing hands and face -- an upward trend over time, progressing from washing their hands and faces with verbal prompting to washing on their own. The camp washing facilities were radically different from the bathrooms that the campers were accustomed to. Thus, their ability to rise to a near-perfect score testifies to their willingness to master new skills and accommodate to a different routine.

Toothbrushing
Use of table utensils
Drinking Behavior at mealtime
Toileting and self-care at the toilet
Dressing, undressing, shoes on and off
Upkeep of personal belongings and bunk area --

Throughout the entire residential experience the autistic group consistently earned very high or the highest possible scores in each of these skills. There was little perceptible change in their performance. The only exception was one camper who required assistance in tying shoe laces.

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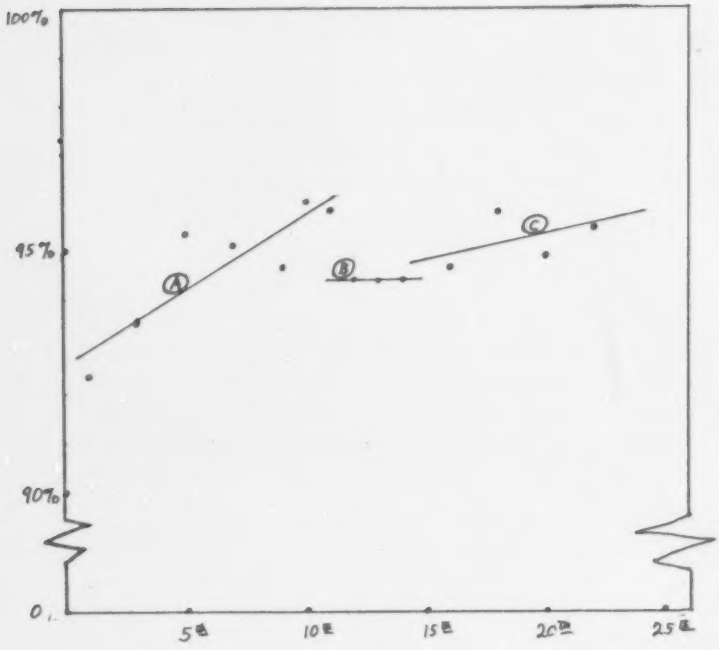
Figure 1

Autistic Self-Care Skills

Percentages of Maximum Obtainable Scores*



*Each camper's individual self-care skills were rated, a daily average was computed for each skill for all campers taken as a group, a total group score for all skills was computed and translated into the percent of maximum obtainable scores to produce this graph.

Showering -- washed and dried themselves reasonably well with some verbal prompting from the counselors. This is in contrast to the situation at home where they all bathe totally unaided. This difference is probably the result of the need to hurry at camp when eight or ten people use the same shower.

Table manners -- consistent scores of seven out of eight possible points. Eating too fast and chewing with their mouths open were the behaviors which lowered their near-perfect rating.

3. a. Maladaptive Behavior, Research Design

Part II of the ABS provides measures of maladaptive behavior related to personality and behavior disorders, and consists of 14 sub-domains: 1) violent and destructive behavior, 2) antisocial behavior, 3) rebellious behavior, 4) untrustworthy behavior, 5) withdrawal, 6) stereotyped behavior and odd mannerisms, 7) inappropriate interpersonal manners, 8) unacceptable vocal habits, 9) unacceptable or eccentric habits, 10) self-abusive behavior, 11) hyperactive tendencies, 12) sexually aberrant behavior, 13) psychological disturbances and 14) use of medications.

Rating of the autistic campers with respect to these 14 sub-domains followed the same pattern as was employed with the ABS Part I, with one additional rating of both autistic and retarded campers after 11 days of the residential program. Each camper was independently rated by at least two different staff members at the 11-day rating and at the end of camp. Almost all staff participated in the rating process. Parents provided pre- and post-camp ratings.

This data permitted comparisons of ratings that would illuminate 1) any change in maladaptive behavior at home before and after the residential experience, 2) changes in maladaptive behavior during camp, 3) differences between the behavior of the retarded and autistic campers and 4) differences in ratings by various counselors.

Maladaptive behavior has been emphasized because it is likely to be of special interest to those developing program strategies.

3. b. Maladaptive Behavior, Results

Table 2 presents the scores for each camper totalled over the 14 ABS Part II sub-domains. As rated by parents, five or six individuals showed a slight decrease in rating (improvement) and one a slight increase after camp.

The staff generally rated all individuals higher at the end of camp than at the mid-point -- this increase in observed maladaptive behavior was most significant for the three campers with the highest initial parental rating. The possible significance of that increase is discussed in section 3c.

The initial staff ratings were generally consistent with the parent ratings and somewhat lower except in the case of two campers, which suggests those two individuals may have had initial difficulty in adjusting to camp.

Although the retarded campers were rated on the ABS Part II as having only one-half as much maladaptive behavior as the autistic campers, the Staff Questionnaire (discussed elsewhere) indicated that the autistics were no more difficult to manage than the retarded. This may be largely because the autistics' maladaptive behavior involved no untrustworthy behavior or violent and destructive acts and a very low level of self-abuse, sexual aberrations, or use of medicines. Their maladaptive behaviors tended to isolate them and appear eccentric, but there was no danger or serious consequence involved.

The autistic group's average scores on ABS Part II ranged from very low (most desirable) to quite high which was in marked contrast to

the profile of average scores for the retarded campers who fairly consistently received scores in the low to mid-range of ABS Part II.

Although three of the autistics earned undesirable scores for passive-rebellious behaviors as measured by the ABS Part II, it is interesting to note that they received generally good ratings on "appropriateness of social interactions" which is discussed in the next section. This suggests that the rebellious behavior occurred late in the program as they began to feel more tension about the approaching close of camp.

Table 2

Summary of AAMD Adaptive Behavior Scale, Part II

Maladaptive Behavior Ratings (Low Scores Desirable)*

	Parent Ratings		Staff Ratings	
Autistic Camper	Pre-Camp	Post-Camp	Mid-Camp	End of Camp
a	24	(24)**	0	6
b	14	8	4.5	10.5
c	18	13	11.5	20.5
d	22	26	50	46
e	26	22	11	31
f	46	20	18.5	57.5
g.	39	28	70	121.5
*Average all autistics	4.4%	3.3%	3.9%	6.8%
*Average autistic campers a, b, c, d			2.7%	3.4%
*Average autistic campers e, f, g			5.4%	11.4%
*Average all retarded campers			2.0%	

Percentages of maximum obtainable score of 612*

*Low scores represent fewer instances of maladaptive behavior.

**( ) Not rated; value assumed.

3. c. Maladaptive Behavior Scores Considered (see table 2)

The substantial increase in maladaptive behavior ratings of campers e, f and g by the staff can have many possible causes, singly or in combination, that are based either on the actions of the individuals themselves and/or on the perceptions of the staff.

With regard to the autistic individuals, the change could be explained by postulating that over the first 11 days they were on relatively good behavior because of the novelty of their new environment, because they were somehow afraid of misbehaving in the new situation, were anxious to please their new supervisors or perhaps something else. By the end of camp, they may have become bored with the repetition of the daily activities and restless, or homesick, or unhappy with the rustic living conditions and lack of privacy; or they may have learned how to test the relatively inexperienced staff to determine how much they could get away with without fear of reprisal. Any or all of these could lead to the observed increase in maladaptive behavior.

With regard to the staff, the increased ratings could be partly due to actual changes in camper behavior and partly due to increased sensitivity to that behavior as they gained familiarity with the autistic individuals and as their emotional relationship with these individuals developed over time. It is likely that with increased familiarity they observed more maladaptive incidents to score.

The staff may well have evidenced a phenomenon common to inexperienced, yet well-meaning surrogate parents as described by Leiken and Reiger (1974)[1] in a paper about their experiences with the supervision of

[1]Stanley J. Leiken, MD, and Norbert J. Reiger, MD. "Supervision of Satellite Foster Home Parents." Paper presented to the American Academy of Child Psychiatry, October, 1974

satellite foster home parents of disturbed children. That is, the staff at first saw themselves as rescuers and healers through application of care and goodwill; and when they encountered lack of improvement or hostility, these rescue fantasies crashed down, resulting in anger at the individual.

Another factor that could apply is that the staff might have dealt with their own situational feelings of inadequacy and ineffectiveness by displacing these feelings onto the autistic individuals. Such displacement was found to be a common and frequent occurrence by Leiken and Reiger.

Finally, but not exhaustively, the staff in some cases may have reached the end of their patience and tolerance for the long hours, lack of days off, poor food, and the constant involvement that was required at camp and reacted unfavorably to behavior they earlier would have overlooked or accepted.

Any or all of these possibilities could have contributed to the increased maladaptive behavior ratings of the three individuals. It was not possible in the context of the camp setting and the short time involved to distinguish specific causes. The experience, however, suggests several considerations important to facilitating future residential experiences:

- The staff should be chosen to be flexible, sensitive and able to discuss their anxieties and fears.
- Peer support or counseling should be available to the staff as a group at frequent intervals to assist in dealing with their feelings toward those they are helping and to build group spirit to provide mutual support during difficult periods.
- The program of activities for the autistic residents, particularly those that are able to function well, should be

reasonably diverse and challenging to channel their energy into acceptable behaviors.

- A program of behavior modification or other methods should be developed to deal with the manifestations of maladaptive behavior.

Table 3

Summary Compilation of Observations of Social Interactions by Autistic Individuals*

	Totals	Staff	All Campers	Retarded Campers	Autistic Campers
Total observed interactions by autistics*	885	714	119	94	25
Average number of interactions per hour with specified groups	25.7		3.4	2.7	0.7
Average duration in seconds	8.6				
Average percent of time in interactions	6.1%		0.8	0.6	0.2
Percent appropriate interactions	95.5%				

*Recorded during 34.5 hours of observation of individual campers

5. Staff Debriefing

Through their collective experience of day-to-day living and problem solving with the autistic group, the staff gained highly significant impressions (in addition to those collected through the previously described research tools). The staff experiences and impressions were shared in several interviews between the Project Director and the camp staff and through the use of a Staff Questionnaire which was designed to gather feelings, ideas and suggestions about the camp experience and the project objectives.

Significant subjective comments by the staff have been incorporated into the Findings section of this report. The following is a partial listing of questions which are amenable to numerical presentation. The other questions of this nature appear in the Findings section.

Questions from Staff Questionnaire not Discussed Elsewhere

1) The autistic campers adjusted well to the changes in retarded groups.

STRONGLY AGREE (5, 5, 5, 5, 5; average 5)

2) I felt adequately prepared to live and deal with the autistic campers.

AGREE (2, 5, 4, 4, 4; average 3.8)

3) The camping experience offered enough challenges to the autistic campers.

AGREE (5, 2, 3, 5, 4; average 3.8)

6. Objectivity and Repeatability

In the research design for this project, objectivity and repeatability of results has been a major concern. Although subjective impressions

of the staff are invaluable and are used, maximum use has been made of formal rating scales and questionnaires so that the responses of both staff and parents are based on answers to many detailed questions. The camp and research staff were summer employees with no on-going association with either MSAC or Melwood and no prior experience working with autistics.

These facts suggest an absence of staff bias about the outcome of this demonstration/research project which should enhance objectivity. Also, the success of this residential camp experience should be relatively easy to duplicate as it does not depend on having staff with special training or prior interest in autism. (The methodological approach of the camp director which contributed importantly to the success of this experience is discussed above: Appendix A, "Staff").

The following comments by the camp director may be of interest to anyone designing a similar program:

> The counselors gained experience during the first three sessions and felt more secure by the fourth and fifth sessions when the autistic campers were included.
>
> Regarding my style of working with the counselors I allowed the counselors to try out their own style of coping and dealing with problems, giving them support and encouragement. I made recommendations often enough that they knew appropriate limits and seldom, if ever, abused their position. I think I was not only receptive to their frustrations but also took over some difficulties, modeling tolerance, limit-setting and positive reinforcement. I also came to them on occasions to have them help me out.
>
> We also had numerous formal and informal gripe sessions for the counselors to ventilate their aggressions and frustrations. There was a definite spirit of non-threatening supervision along with togetherness. Personally gratifying relationships were present for several counselors, and this perhaps contributed to the counselors' patience, tolerance and coping ability.
>
> In an on-going, permanent residential program, personal, nurturing relationships would need to be available to the staff to replace lack of social gratification from autistic individuals. Perhaps ongoing contact with parents of autistic adults would help supplement this need, and availability of such contact might be a requirement for entrance to such a program. Time off, and variability of program also deserve careful planning.

APPENDIX C

HISTORY: MSAC-MELWOOD COOPERATION

The Melwood Horticultural Training Center, Inc., located in Prince Georges County, Maryland, administers a year round horticultural-vocational training program for retarded adults, a group home, and a summer camp for retarded adults at the Melwood Farm in Charles County, Maryland.

After exploring and studying many alternatives, MSAC, in early 1975, asked Melwood to develop a vocational and/or residential program that would include autistic adults. The Melwood staff tried to develop plans based on the experience of some on-going program, but could find no existing models that integrated autistic and retarded adults in a horticultural training program or in a small community residence. Consequently, MSAC and Melwood agreed to work together systematically to develop the experience and information needed to create such a program.

Melwood Summer Farm Program of 1975

The first phase of this effort occurred during the summer of 1975 when MSAC provided scholarships for six autistic adolescents to attend an eleven-day session at the Melwood Farm Summer Camp. The experiment went well. It appeared that autistic and retarded individuals could be successfully combined at the camp. Unfortunately, the camp staff dispersed at the end of the summer; and it was impossible to obtain information about what problems existed, what strategies were employed to successfully deal with problems, and any other information that would provide a basis to plan a permanent on-going program.

MSAC next contracted with Melwood to investigate, analyze and recommend a program of day and residential services for autistic adults. The study, conducted by Ms. Andi Morris of the Melwood staff, resulted in the report "A Preliminary Study to Determine the Feasibility of Conducting a Full Scale Investigation of Day and Residential Programming Needs for Autistic Adults, November, 1975". A literature search, conducted as part of the study, indicated that essentially all literature pertaining to autism deals with children and is not relevant to the very different problems and needs of the autistic adult. The report stressed the need for more experientially derived data.

Subsequently, MSAC applied to the Maryland Developmental Disabilities Council for funds to operate a longer trial residential program at the Melwood Camp in 1976 with a research component and to conduct a nationwide survey in an attempt to determine whether any models exist that could provide additional information on designing and operating an appropriate program in Maryland. This report presents the results of that activity.

APPENDIX D

TREPAA-76 ADVISORS

Parent-Professional Advisory Committee

Joel Billy, Director
Project Bridge
Edwin W. Broome Junior High School

John Chaporis, MSAC
Takoma Park, MD

Earl Copus, Director
Melwood Horticultural Training Center, Inc.

George Cruze, MSAC
Annapolis, MD

Senator J. Joseph Curran, Jr.
Maryland Senatorial Dist. 43

Ellen Dashner, MSAC
Silver Spring, MD

Theodore G. Lucas, Asst. Secretary
Special Programs
Maryland Department of Health and Mental Hygiene

Jacquelin Gorman, MSAC
Baltimore, MD

Lakin Philips, Ph. D., Director
Counseling Center
George Washington University

Donald Pumroy, Ph. D., Professor
Dept. of Education and Psychology
University of Maryland

Mary Rodeberg, Director
Residential Services
Montgomery County Association for Retarded Citizens

Woody Schwarmer, Director
Center for the Handicapped

Senator Newton I. Steers, Jr.
Maryland Senatorial Dist. 16

Lou Weidel, MSAC
Silver Spring, MD

Sigrid Welsh, MSAC
Silver Spring, MD

Maryland Developmental Disabilities Council Advisors

Philip Holmes, Associate Director
Developmental Disabilities Council

Sheridan L. Neimark, Member
Developmental Disabilities Council

Carl Rose, Member
Developmental Disabilities Council

MSAC Coordinator and Liaison

Jane Salzano, President
Maryland Society for Autistic Children

TREPAA-76 STAFF

Cooperating Melwood Staff

Earl Copus, Director of Melwood Horticultural Center, Inc.
Daniel Pearce, Director, Melwood Farm
Larry Hudak, Director, Melwood Farm Camp

Project Staff

Anita King, ACSW, a social worker with experience in program development and administration, served as Program Director. She had overall responsibility for the project, did related community-organization, conducted the nationwide survey and literature search, and was responsible for this Report. Formerly, she worked with developmentally disabled children and their parents in California as a group therapist, program developer and as a member of several advisory councils.

Debby Beuchert, a recent graduate of the University of Maryland with a degree in psychology, served as Chief Researcher. She participated in creating the research design and in writing this Report. Her major responsibility was collecting and synthesizing data. She visited the home of each autistic camper to obtain pre- and post-camp data and lived at camp, collecting data during the entire camp session.

Jack Roth, a doctoral candidate in psychology at the University of Maryland who has worked with developmentally disabled and emotionally disturbed adolescents at the School for Contemporary Education, served as Research Consultant. His responsibilities included research design, supervising data collection and assisting in data analyses.

David Silverman, a college student, created a visual documentation of the program in an extensive series of slides taken throughout the camp experience.

Larry Hudak, Director, Melwood Farm Camp (see above) is a Marriage and Family Counselor at the Arizona Guidance Center, 1745 West Northern Avenue, Phoenix, Arizona 85021. He worked for Melwood for the duration of the summer camp. In addition to being responsible for the camp program, he cooperated closely with the Project Staff in all phases of the design and execution of TREPPA-76.

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APPENDIX E

AUTISM

The following pages present the National Society for Autistic Children's Definition of Autistic Children and the text of "Facts About Autism", a pamphlet from the National Clearing House for Mental Health Information (HEW, NIMH), U.S. Government Printing Office Publication: 19720-470-546.

These materials were given to the camp staff before their work with the autistic group in TREPPA-76 to provide an understanding of the background of the autistic individuals in the project and to provide an overview of current thinking about autism.

As yet there is little written about the transition of autistic children into their adult years. This is easily explained by the fact that little attention was paid to autism before the founding of the National Society for Autistic Children in 1965. Furthermore, the condition was virtually unknown until 1943 when it was first described and named by Dr. Leo Kanner.

These pages deserve the attention of any reader desiring a brief introduction to autism.

Working Definition of Autistic Children as Revised by the NATIONAL SOCIETY FOR AUTISTIC CHILDREN Board and Approved by the NSAC Professional Advisory Board January 18, 1975

General Definition:

The term "Autistic Children" as used by the National Society for Autistic Children shall include persons, regardless of age, with severe disorders of communication and behavior whose disability became manifest during the early developmental stages of childhood. "Autistic Children" includes, but is not limited to, those afflicted with infantile autism (Kanner's syndrome), childhood psychosis, childhood schizophrenia or any other condition characterized by severe defects in language ability (such as profound aphasia) and behavior and by a failure to relate appropriately to others. The Autistic child appears to suffer primarily from profound central processing disorders, i.e. a selective impairment of his cognitive and/or perceptual functioning, the consequences of which are manifested by sensory-motor, cognitive, social and language developments, impediments which reduce the ability to understand, communicate, learn and participate in social relationships.

Specific Characteristics:

Such children are typically multi-handicapped in their abilities to receive and communicate information, resulting in behavior inappropriate to physical and social demands of their environment. As in aphasia, the dominant communication disorder or profound learning disability appears to constitute a severe central disorder in symbolic ability resulting from the incapacity to use and to understand language appropriately, particularly a seeming inability to process language through auditory channels. The difficulty is often accompanied by impairment in motor, visual, and auditory perception. The behavior of an autistic child is typically improved by the application of appropriate educational procedures. A combination of some or all of the following idiosyncratic behaviors characterize the autistic child. These behaviors vary from child to child and time to time in severity and manner.

1. Severely impaired speech or complete lack of speech.
2. Impaired or complete lack of relatedness and social inaccessability to children, parents and adults; seeming lack of desire for affection; aloneness; withdrawal.
3. Extreme distress for no readily discernable reason.
4. Lack of intellectual development or retardation in certain areas, sometimes accompanied by normal or superior abilities in other areas.
5. Repetitive and peculiar use of toys and objects in an inappropriate manner and/or similar repetitive and peculiar body motions, such as incessant rocking, ritualism.
6. Unusual reaction to perceptual stimulae, such as seeming not to hear certain sounds and over-reacting to others (e.g., holding hands over ears) or "looking-through" objects, poor eye contact, or inability to appropriately perform certain gross and/or fine motor activities (walking with peculiar gait, limpness in fingers, inability to hold a pencil appropriately).
7. Onset of disorder at birth or apparent normal early development followed by deterioration in functioning or decreased developmental rate within approximately the first three years of life.
8. Hyperactivity or passivity.
9. Apparent insensitivity to pain.

What is autism?

Autism is a severe disturbance of mental and emotional development in young children. Autistic youngsters are extremely withdrawn. They show little or no interest in other people or in the normal activities of childhood. They are often described as being "in a shell" or "living in a world all their own."

How much is known about the condition?

Despite considerable research in such fields as psychology, genetics, neurology, neurophysiology, and biochemistry, very little is definitely known about autism. Specialists differ sharply in their opinions on the nature of the condition, its cause and its treatment. As a result, parents seeking help for such a child may be given many different diagnoses. Their child may be termed mentally retarded, emotionally disturbed, brain-damaged, suffering from childhood schizophrenia, or symply "psychotic." Some specialists hold that autism is not a specific disorder but a particular way of behaving that can result from a combination of causes which vary from child to child.

How many autistic children are there?

Because doctors differ on diagnosis, estimates vary. Specialists who define autism according to a very limited and specific set of symptoms say it is a rare condition. Those who use the term more broadly disagree and report figures for the United States and England that range from 2 to 4.5 cases for each 10,000 of population. The condition is estimated to occur two to four times more often in boys than in girls.

How important is the problem these children present?

The overall problem of mental illness is a very serious—and very expensive—one for the whole country. As matters now stand, a high percentage of autistic children face the possibility of spending many years in institutions. Their wasted lives will represent a tragic loss to themselves, their families, and their communities.

What leads to a suspicion of autism?

The most obvious characteristic of the so-called autistic child is his extreme self-isolation. Such youngsters pay more attention to objects than to other humans. In some this is noticeable as early as infancy when the child is stiff and unresponsive even with his mother. The autistic child seems to look through, or past, people. It is very difficult to "catch his eye."

In what other ways are autistic children "different"?

Their behavior is unusual in many ways. No child is exactly like another but, as a group, autistic children display many of these characteristics:

Speech: Some autistic children never speak. Others can say or repeat words but do not talk in the normal sense. That is, they may be able to reel off lists of names, recite television commercials or nursery rhymes but they do not use language to communicate—to ask for what they want, to give information or to express ideas and feelings. The autistic child does not seem to understand "I" as a word standing for himself. Like a much younger child, he may answer a question by repeating the last part of it. ("Do you want some milk?" "You want some milk.") His voice may be toneless or have a strange quality. Sometimes a child who is usually completely silent will, in an emotional moment, speak out clearly and appropriately, then relapse again into silence.

Hearing and vision: Many autistic children seem to be deaf. They do not react to loud noises nor respond when called. Careful testing, however, usually indicates ability to hear, in the technical sense, and at times the children appear to understand what is said to them. Other children may respond to some sounds or voices but not others. It is possible that autistic youngsters simply "tune out" what they do not want to hear; or some flaw in their hearing mechanism or some damage to the brain may cause them to get only partial or garbled messages. As for vision, there may be similar disturbances even though, in the usual sense of the word, the children can "see" normally.

Touch and smell: Autistic children often seem to get much satisfaction from these senses, smelling each new object they encounter, running their hands—or tongues—over rough and smooth surfaces.

Need for sameness: Any change in routine, in objects they are used to, or even in the placement of things upsets some of these children tremendously.

Play: Autistic children show little interest in toys and rarely use them as normal children do. They may turn a toy truck or doll carriage or tricycle upside down and just keep spinning the wheels; or they might hold a plastic jump rope in the air and turn it and twist it endlessly. Others may set out objects in very complicated patterns and become extremely upset if the arrangements are disturbed. Since they ignore and avoid other children, they do not play games and resist even such simple two-person activities as rolling a ball back and forth.

Physical activity: Some autistic children re over-active, always on the run and into verything; others sit long periods without oving; still others may go back and forth etween these extremes. Some are very raceful and sure-footed, running and climbng like experts; others persist in strange ovements—rocking their bodies, flapping heir hands, taking strange poses. Sometimes they even do things that hurt themelves, such as head-banging.

Daily routines: Frequently there are difficulties centered on eating, sleeping, and oilet training. The child may do little for himself, sometimes using other persons as tools; that is, instead of turning on a light or opening a door on his own, he may take someone else's hand and place it on the switch or doorknob.

Emotional reactions: Some of these children show almost no emotions; others may laugh or smile, cry or go into tantrums for no apparent reason. They may be extremely fearful or show no sense of fear at all.

Are autistic children mentally retarded?

A few specialists hold that unless a child shows potentially good or superior intelligence he should not be included in the autistic category. Certainly many have an intelligent appearance and air of alertness and some are very skillful at certain isolated mental activities, such as memorizing difficult material or manipulating large numbers. It is almost impossible to test the autistic child's intelligence by standard methods. As more varied approaches are tried, however, results indicate that most function at a severely retarded level.

Are autistic children born that way?

Some seem to behave in an abnormal way even as infants, and certain specialists insist that only these children can truly be termed autistic. Many times, however, children later termed autistic had seemed over a period of several years to be developing normally, then stopped or began to lose skills they already had.

How is a diagnosis of autism made?

Thorough testing by a variety of medical specialists is essential. Sight, hearing, the working of the brain and nervous system, and the body's chemistry must be investigated. The possibility of family conditions upsetting to the child must also be explored. Usually only after clearly identifiable, direct physical causes have been ruled out is a diagnosis of autism considered.

Are parents responsible for this condition?

An early theory, widely reported, held that the parents of autistic children were cold, distant people who caused their child's disturbance by not giving him the affection and pleasant experiences babies need. A later variation of this was that the baby might have been born with an unresponsive nature and this lack in him caused parents to treat him in a mechanical way that made the problem worse. Of course, the early treatment a child receives influences his development. Recent research, however, provides little or no support for the idea that the parents of an autistic child are, invariably, "the cause of it all."

What is the cause?

At present the cause is unknown. The human body and mind are extremely intricate and many of their workings can still not be measured or tested with perfect accuracy. The brain and nervous system cannot be taken apart for examination. The inner ways a young child responds to his experiences cannot be looked at under a microscope.

What are some of the theories?

*At this time many researchers feel that disturbances in the central nervous system or in the body's chemical balance may be at the root of the trouble. Because of these defects, they believe, the child gets only a distorted or unusual picture of reality. The messages his mind gets are vague and confused. People and experiences do not "make sense" to him so he cannot respond in ways that make sense to others. What may be the cause of the physical defects is the subject of still further research.

Those who place less emphasis on the possibility of physical causes as the root of difficulty agree that the child's constitution may be a contributing factor. They suggest that he may be extra sensitive to everything that goes on around him and so puts up mental barriers as protection against too much attention and stimulation; or, he may not be sensitive enough and so stimulation that would be enough for a normal child is too meager for him.

Whether or not they look on physical defects as a contributor, specialists generally regard the child's strange ways as devices for avoiding reality which has proved too painful or empty or because he cannot meet normal demands. Through his peculiar actions, the child is seen as finding satisfaction in his own little world.

Can drugs help the autistic child?

Experiments are being made with a variety of drugs and with megavitamin therapy. Children differ in their reactions and specialists differ in their judgments of effectiveness. As yet, there have been no dramatic results in terms of consistent or marked improvement.

What treatment is recommended?

A limited number of experimental treatment programs are underway here and there throughout the country. Among approaches used are:

Traditional psychotherapy: The child lives at home and sees a psychologist or psychiatrist regularly. Studies indicate little success for this method.

Residential therapy: The child lives among specially trained therapists who make no demands on him, respond to his needs and wait for him to make his own way into the real world. Children in such programs are usually very carefully selected and they remain in treatment for years. Some show real improvement.

Body stimulation: The child is helped to become more aware of the world and of himself through intensive, carefully constructed programs designed to stimulate his senses of touch, taste, and body movement.

Conditioning: By means of rewards—extra attention, affection, praise or special treats—the child may be encouraged or trained to speak words, care for some of his own needs, and behave in more acceptable ways. In some programs punishments are also used.

What are the results of treatment?

All the methods mentioned have helped some children make some improvements. None can yet be regarded as the answer for all.

Can schools help?

Special nursery schools and special classes, in regular schools or mental health centers, use a variety of educational approaches to help bring autistic children out of their shell. The programs for preschoolers often resemble those of regular nursery schools but, ideally, activities are planned to meet each child's particular needs at each stage of progress.

What is the future for autistic children?

Complete recovery is extremely rare. Since children vary greatly in their abilities, statistics mean little in predicting individual chances of recovery. However, the few followup studies that have been made indicate that large numbers of autistic children are never able to attend regular school and many must be institutionalized. The picture seems darkest for those who are still not speaking by the age of 5. If marked improvement is to occur it is usually evident by age 6 or 7.

What must be done to improve the autistic child's chances?

Many different approaches to this problem are necessary. All of them are expensive and all require hard work by specially skilled, trained people. A major need is for money, from government agencies and private organizations, to support such efforts as:

Research: Much more study must be done on all aspects of human development, both normal and disturbed, with increased emphasis on the biochemical and physiological aspects of mental disabilities.

Diagnostic services: To identify autistic children as early as possible, more special centers are needed where all required testing and observation would be readily available.

Guidance to families: Efforts to help an autistic child should begin as soon as his problem is recognized. The whole family, including brothers and sisters, should know what his problems are and what would be best for him. Counseling services and educational programs for parents are vitally needed to achieve this.

Community facilities: Play programs, nursery schools, and special classes are essential for young children. Later on vocational training, young adult centers, and special work programs are required. For those who cannot remain at home institutional care must be improved and, where possible, other arrangements—foster homes and special residences—provided.

How can one learn more about autism?

Books on the general topic of seriously disturbed children often include material on autism. Some special books on the problem are:

THE NATURE OF CHILDHOOD AUTISM. By Gerald O'Gorman. Appleton-Century-Crofts. New York: 1970

INFANTILE AUTISM. By Bernard Rimland. Appleton-Century-Crofts, New York: 1964

YOUR CHILD IS ASLEEP: Early Infantile Autism: Etiology, Treatment and Parental Influence. By Austin M. DesLauriers and Carole F. Carlson. Dorsey Press, Homewood, Ill: 1969

THE EMPTY FORTRESS: INFANTILE AUTISM AND THE BIRTH OF THE SELF. By B. Bettelheim. The Free Press, New York: 1967

AUTISTIC CHILDREN. By Lorna Wing. Brunner/Mazel, New York: 1972

Parents of an autistic child, or others with a serious interest in the problem, might be interested in the publications and activities of the National Society for Autistic Children, Inc. Information about local chapters is available from society headquarters, 621 Central Avenue, Albany, N.Y. 12206.

Senator RANDOLPH. Miss Carol Cervenka.

STATEMENT OF CAROL CERVENKA, PROGRAM RESOURCE DEVELOPMENT SPECIALIST, EPILEPSY FOUNDATION OF AMERICA, WASHINGTON, D.C.

Ms. CERVENKA. Mr. Chairman, my name is Carol Cervenka, and I am speaking on behalf of the Epilepsy Foundation of America.

I know first-hand what epilepsy means and what the Developmental Disabilities Act has meant to people with epilepsy because I have epilepsy.

My background includes being a volunteer in two recent chapters and more recently a chapter executive and I have had the challenge of serving on the Texas DD Council for 7 years, and I have about 4 to go.

It is the foundation's position that the Develcpmental Disabilities program is the most effective instrument that has appeared to date to promote the delivery of comprehensive service in meeting the needs of persons with epilepsy.

Although initial progress has resulted in meaningful new developments in epilepsy, progress to date has been less than adequate, largely because the epilepsy movement had not had more representation on the DD councils at both State and National levels, and part of this reason is that epilepsy, when the Developmental Disabilities Act came in, was a new organization nationally, and so part of the burden is ours.

We were not as ready to assume the leadership which was needed as we should have been and could have been.

Senator RANDOLPH. Off the record.

[Discussion off the record.]

Senator RANDOLPH. Back on the record.

Ms. CERVENKA. I might say that Developmental Disabilities has stimulated services for people with epilepsy as well as the advocacy efforts of the people in Florida, Alabama, Hawaii, and New Jersey.

Social service programs for people with epilepsy have been generated in a broad spectrum, especially in rural areas in parts of the United States.

Texas is only one example, but the one I am most familiar with.

Developmental Disabilities funds have gone into the development of sorely needed residential facilities for people with epilepsy, in the District of Columbia, and Cincinnati, Ohio. and Texas. And they finance the gathering of material and data which has assisted in the establishment & development of comprehensive centers for epilepsy.

The program has provided educational services and training about epilepsy for school personnel. And there is a whole list of marvelous things that have come about as a result of DD.

However, though progress has been significant under the DD program, the Epilepsy Foundation of America feels that it could be far more substantial if the following changes in the operation of the program were made:

All planning efforts, State and national, should have adequate representation of persons with primary personal and professional interest in the problems addressed by the act.

It is also the foundation's position that since 50 States have been required to submit annual State plans since the advent of the act, there is a significant deficit in that there has never been a national plan derived from these 50 State plans from which national priorities could be articulated and publicized.

We believe the time has come when a comprehensive national plan should be developed and specific goals and objectives, long range, intermediate, and short range, should be promulgated with accompanying time lines for accomplishment of these ends.

One of the criteria for eligibility under the developmental disabilities program is age of onset. Although epilepsy appears prior to age 18 in nearly 80 percent of the epilepsy population, it does appear in many others later in life.

In mine, I was 22. I went through 5 years of incredible problems.

The degree and types of services required by this latter population is not significantly different from those in whom the condition originates prior to age 18.

Therefore, the foundation recommends that the age restriction should be looked at as it pertains to the problems of epilepsy.

The eligibility requirements pertaining to "substantially handicapped" have been rather vague and nebulous and to date have not been satisfactorily defined for program planners and administrators.

It appears from reviewing the services which are authorized under the act that the intent of Congress was not to serve only extremely severely impaired individuals. Epilepsy, being a hidden condition in most persons, and one which is surrounded by stigma and myth, causes devastating psychological and social conditions in many persons who otherwise appear to be normal.

Therefore, the foundation recommends that the degree of substantiality which constitutes handicapped, should be explicity set down in writing and well publicized.

We further feel that this definition of substantiality should include the severe problems of stigma and lack of opportunity and social reactions surrounding the problem of epilepsy.

Specific guidelines for the monitoring of programs funded by developmental disabilities moneys on the Federal, regional, and local levels must be developed and adhered to.

In summary, the act has been important and significant in focusing a heightened degree of public attention to the problem of epilepsy.

We are gratified with the progress made to date and feel that with certain modifications and more intensive planning and tightened administration, the progress could be significantly accelerated for all disabilities covered by the act.

We further feel that epilepsy has several unique distinguishing characteristics which are not well accommodated by the act in its present form, and with certain minor modifications greater progress could be achieved and many handicapped individuals who suffer from the problem of seizure disorders would benefit.

We strongly urge continuance of the act and increased appropriations.

Senator RANDOLPH. Could you expand on specific guidelines for the monitoring of programs?

Ms. CERVENKA. How the monitoring of programs might be funded?

Senator RANDOLPH. No, I was inquiring about specific guidelines for the monitoring of the programs that are funded by the developmental disabilities program.

Ms. CERVENKA. I think that in many instances the councils have the ability to gum you to death but not bite you, and that it would be—but it would be wonderful if we had more specific guidelines within the program disability areas that were relevant to those program disabilities.

For instance, the guidelines are like pouring water on gravy in many instances. They are specific for retardation, but oftentimes not relevant to epilepsy or autism, and I think we need to look at a little bit more individual monitoring of each disability.

Senator RANDOLPH. The under 18 years of age restriction is a problem we want to check into.

Ms. CERVENKA. That is really a problem.

It is heartbreaking to see someone come in who has epilepsy developed at age 19 and has no recourse to the developmental disability program.

Senator RANDOLPH. The specific guidelines and the matter of the 18 year old cutoff will be gone into very, very carefully. You will have from us questions that you can answer for the printed record.

Thank you for coming.

Ms. CERVENKA. Thank you.

[The prepared statement of Ms. Cervenka and information referred to follow:]

STATEMENT

RESPECTFULLY SUBMITTED TO THE

SENATE SUBCOMMITTEE ON THE HANDICAPPED

FOR:

OVERSIGHT HEARINGS ON

THE DEVELOPMENTAL DISABILITIES PROGRAM

ON BEHALF OF:

EPILEPSY FOUNDATION OF AMERICA
1828 "L" Street, NW
Washington, D.C. 20036

PRESENTED BY:

Carol Cervenka
Epilepsy Foundation of America

MARCH 31, 1977

91-852 O - 77 - 8

Mr. Chairman, members of the Subcommittee on the Handicapped, my name is Carol Cervenka, and I am speaking today on behalf of the Epilepsy Foundation of America to convey our organization's concerns and interests in the Developmental Disabilities program.

I know first-hand what the Developmental Disabilities Act has meant to persons with epilepsy.. I have epilepsy. My background includes being a volunteer in two local chapters of the Epilepsy Foundation as well as a member of its National Board of Directors. More recently I have been a chapter executive and am now on temporary assignment to the National Office of the Foundation to develop a new national program. I have also had the opportunity of serving for the past seven years as a member of the Texas Developmental Disabilities Council.

It is the Foundation's position that the Developmental Disabilities program is the most effective instrument to promote the delivery of comprehensive services that has appeared to date in meeting the needs of those with epilepsy.

Although initial progress has resulted in meaningful new developments in epilepsy, progress to date has been less than adequate largely because the epilepsy movement has not been well represented on Developmental Disability Councils at both the national and state levels. Part of this is the reason that the Developmental Disability Act was amended to Public Law 88 - 164 which was the Mental Retardation Facilities and Construction Act and, therefore, epilepsy, represented by a then new national organization, was not as ready to assume leadership roles and assert its presence as were certain other conditions included under the Act.

At present the Foundation believes the Developmental Disabilities program has been responsible for the following advances in services to the person with epilepsy:

- State Councils have stimulated services for persons with epilepsy as well as the advocacy efforts of the private sector in Florida, Alabama, Hawaii, and New Jersey.

- Social service programs for people with epilepsy have been generated in a broad spectrum of service providing agencies, especially in rural areas, in some parts of the country. Texas is one example.

- Developmental disability funds have gone into the development of residential facilities for people with epilepsy in the District of Columbia and Cincinatti, Ohio, as well as financing the gathering of material and data which have assisted comprehensive centers for epilepsy to develop.

- The program has provided educational services and training in epilepsy for school personnel in Pennsylvania, Utah and Iowa.

- It has fostered consumer staff members in consumer self-help groups in more than 15 cities throughout the United States.

- Developmental disability funds have provided the calibration of laboratories regulating the amount of anti-convulsant drugs in the blood mainstreams of epilepsy patients.

- The program has educated consumer members of Developmental Disability Councils and representatives of voluntary organizations in making use of existing Federal programs on the State level which satisfy the needs of persons with epilepsy.

- It interprets the needs of persons with developmental disabilities of all types to Federal Agencies which have responsibility and authority for operating programs which are or can be of assistance to the developmentally disabled.

- The developmental disability concept has been expanded through state laws bringing about greater benefit to the developmentally disabled including persons with epilepsy.

Therefore, progress has been significant under the Developmental Disability program, but the Epilepsy Foundation of America feels that it could be far more substantial if the following changes in the operation of the program were made:

1. All planning efforts - state and national - should have adequate representation of persons with primary personal and professional interests in the problems addressed by the Act.
2. It is the Foundation's position that since the 50 states have been required to submit annual state plans since the advent of the Act, that there is a significant deficit in that there has never been a national plan derived from these 50 state plans from which national priorities could be articulated and publicized.
3. We believe the time has come that a comprehensive national plan should be developed and that specific goals and objectives - long range, intermediate, and short range - should be promulgated with accompanying time lines for accomplishment of these ends.
4. One of the criteria for eligibility under the Developmental Disabilities programs is "age of onset". Although epilepsy appears prior to age 18 in nearly 80% of the epilepsy population, it does appear in many others later in life. The degree and types of services required by this latter population is not significantly different from those in whom the condition originates prior to age 18. Therefore, the Foundation recommends that the age restriction should be lifted as it pertains to the problems of epilepsy.

5. The eligibility requirements pertaining to substantially handicapped has been rather vague and nebulous and to date has not been satisfactorily defined for program planners and administrators. It appears from reviewing the services which are authorized under the Act that the intent of Congress was not to serve only extremely severely impaired individuals. Epilepsy, being a hidden condition in most persons, and one which is surrounded by stigma and myth, causes devastating psychological and social conditions in many persons who otherwise appear to be normal.

For instance, an individual who is unable to obtain employment because he or she has a history of epilepsy is substantially handicapped in many areas of his or her life. The same individual in all probability is unable to be a licensed driver of a motor vehicle and, therefore, has other restrictions on his or her life. He or she may be denied recreational opportunities, membership in organizations and may face stigma of a magnitude that he or she feels unfree to regularly attend the church of his or her choice, etc.

Therefore the Foundation recommends that the degree of substantiality which constitutes "handicapped" should be explicitly set down in writing and well publicized. We further feel that this definition of substantiality should include the severe problems of stigma and lack of opportunity and social reactions surrounding the problem of epilepsy.

6. Specific guidelines for the monitoring of programs funded by Developmental Disabilities monies on the Federal, regional and local levels must be developed and adhered to.

Summary: The Developmental Disabilities Act has been important and significant in focusing a heightened degree of public attention to the problem of epilepsy. We are gratified with the progress made to date and feel that with certain modifications and more intensive planning and tightened administration that the progress could be significantly accelerated for all disabilities covered by the Act.

We further feel that epilepsy has several unique distinguishing characteristics which are not well accommodated by the Act in its present form and with certain minor modifications greater progress could be achieved and many handicapped indivduals who suffer from the problem of seizure disorders would benefit.

We strongly urge continuance of the Act and increased appropriations.

Epilepsy
FOUNDATION OF AMERICA

Suite 406 • 1828 L Street, N.W. • Washington, D.C. 20036 • (202) 293-2930

April 11, 1977

The Honorable Jennings Randolph
United States Senator
Chairman, Subcommittee on the Handicapped
Room 4232, Dirksen Senate Office Building
Washington, D.C. 20510

Dear Senator Randolph:

This is in response to your letter of April 1, 1977 in which you requested additional information about the activities of State Councils in improving services to persons with epilepsy; the need for specific guidelines for monitoring programs funded by Developmental Disabilities monies; a list of the Federal grants that the Epilepsy Foundation has recieved and the activities conducted under these grants; and a profile of the Foundation's hiring of the handicapped in professional and support positions.

Developmental Disability Councils in the following states have provided the services listed below:

NEW JERSEY: The New Jersey Developmental Disabilities program provided the funds for an information and referral service to persons with epilepsy and other developmentally disabled individuals. The purpose of this program is to restore persons to employability and/or maximum social adjustment and independence.

FLORIDA: The Florida 5-Year Action Plan for Epilepsy, developed in 1973, was a cooperative effort of the Florida DD Planning and Advisory Council, the Florida Epilepsy Foundation, and the Department of Health and Rehabilitative Services, Division of Retardation.

In addition, the Council has funded information and referral programs throughout the state of Florida, the development of self-help groups and counselling services for vocational development, and a public education program.

HAWAII: The Developmental Disabilities Council of Hawaii has been responsible for the provision of extensive social services to persons on the island of Oahu.

ALABAMA: Informational and referral services have been provided to persons with epilepsy in the Mobile, Huntsville and Birmingham areas.

Specific guidelines for the monitoring of programs funded by Developmental Disabilities monies are needed because state DD Councils at present have planning responsibility but no authority to see that the plans are carried out. While monitoring and evaluation are built into each grant awarded, no mechanisms exist for Council review of the evaluation. It has been the experience of several epilepsy representatives on state DD Councils that it has been difficult, if not impossible, to obtain substantive evaluation information regarding current and previous programs funded with DD monies.

While State Councils are able to direct attention to available Federal programming and review state plans, no mechanism has been built in to encourage or enforce DD programming as components of those state plans.

Councils should have the authority to exercise sign-off approval on the various state plans pertaining to Federal programs, as these plans affect the developmentally disabled.

The Epilepsy Foundation of America has received grants or contracts from the Federal government to conduct or continue the following programs:

"Training and Placement Services" - EFA has started a major new national program to improve job opportunities for young people with epilepsy. The program, known as the Training and Placement Services (TAPS), is funded by a contract of up to $624,000 from the Department of Labor Manpower Administration under the Comprehensive Employment and Training Act (CETA). With a goal of placing 600 youths, the project is administered in five cities: Atlanta, San Antonio, Cleveland, Minneapolis/St. Paul, and Portland.

"Technical Assistance to Developmental Disabilities Councils, Volunteer Agencies on the Development of an Appropriate Delivery System for DD Citizens with Seizure Disorders - The major goals of the grant are to strengthen the planning and implementation of a service delivery system for developmentally disabled persons with seizure disorders throughout the United States. This goal is being accomplished by the establishment of a system for providing technical assistance to state DD Councils and staffs, state designated agencies, University Affiliated Facilities, private voluntary agencies and other service providers in more appropriately addressing the needs of this population. An evaluation system for the total project has been established. The $91,500 grant is for a one-year period, which started October 1, 1976.

"National Antiepileptic Drug Levels Quality Control Program" - The purpose of this program is to improve the performance of the majority of U.S. laboratories routinely performing antiepileptic drug level determinations in order to assure accurate, timely and financially affordable performance of this analysis. The grant totalling $85,000 runs for a one year period which began October 1, 1976.

"Technical Assistance on Utilization of Federal Programs to Developmental Disabilities Councils and Voluntary Agencies" - The purpose of this program is to develop training materials for consumer representatives on DD Councils and representatives of voluntary agencies serving the developmentally disabled on how to access federally funded programs. In addition, the project provides for the development of a series of client-centered pamphlets which explain in basic English the federally assisted programs for which individuals with developmental disabilities may be eligible.

The National Association of Retarded Citizens is the applicant agency for this grant. The project includes a 12 member steering committee with equal representation from mental retardation, epilepsy, cerebral palsy and autism. The project employs four technical coordinators, one on each agency's staff, and a project director. EFA receives the benefits of approximately $29,000 per year in personnel, plus travel, space, supplies, etc. The grant is for a three-year period initially funded October 1, 1976.

"Consumer Self-Help Groups" - A project to plan, develop and implement self-help groups operating in the framework of chapters of the Foundation and funded by Developmental Disabilities grant money, will be completed in June, 1977. Fifteen group coordinators who all have epilepsy were selected and trained in fifteen chapters throughout the country. Group coordinators developed self-help groups and provided peer counseling services. The Self-Help groups worked on a variety of issues ranging from personal change (employment, acceptance of their disability, understanding of their medical problem and effects of medication, etc.) to advocacy and social change. Several manuals on the development and operations of self-help groups have been written. A majority of the self-help groups coordinators will continue to work with the chapters on completion of the project. They will be funded by private and public sources accessed on the local and state level. This final year of this three-year grant is in the amount of $169,618.

Of a total staff of 44 employees at the National Office of EFA, 11 (25%) of the professional employees have a serious handicapping condition, as do 4 (9%) of the employees at the support level. As mentioned earlier in this letter, the Foundation, under a Developmental Disability grant, has established self-help groups in fifteen cities. All professionals in these groups have epilepsy. A copy of the Foundation's Affirmative Action Plan pertaining to employment practices relating to the handicapped was forwarded to your offices previously.

The Epilepsy Foundation of America appreciates the opportunity to appear before the Senate Subcommittee on the Handicapped. We hope that this additional information will prove useful.

Sincerely,

Carol Cervenka

Carol Cervenka
Program Resource Development Specialist

CC/jl
enclosure

Senator RANDOLPH. Mr. Cohen, please.

Give me the opportunity to speak of the members of the government class from the Model Secondary School for the Deaf.

I remember, Pat, that we were there for the groundbreaking.

When was that exactly?

Mrs. FORSYTHE. Two years ago, in 1975.

Senator RANDOLPH. Last September, the school opened. The students come from many, many parts of the country.

I think we have a student from Alaska. I wonder if he would stand. Thank you.

The work being carried on there is tremendously important, and we are happy that the students are here with us today.

All of us are gratified when students from this school or other schools are present for our hearings. We have been fortunate this year that many student groups have come.

Mr. Cohen, if you would begin your testimony, and introduce your associates.

I will take this opportunity to present the ranking member of the minority, which is not really a minority. It is a partnership. Senator Stafford, of Vermont, will take charge of the hearing at this point.

Perhaps he will have to leave a little later and someone will come back and take over for him.

Thank you so much, Bob, for taking over and permitting me to go to the other hearing that I must attend.

Senator STAFFORD. Thank you very much, Mr. Chairman.

In spite of a reorganization of the Senate, we still seem to find ourselves with conflicts between our committee assignments.

I have three different ones that are meeting simultaneously this morning and I know that the chairman is in about the same situation.

Once we get the Senate to speed up on committee work, maybe our reorganization will allow us to avoid these conflicts.

But I can assure you, Mr. Cohen, and everybody here, that the members of the subcommittee who are not here, are not here because of similar conflicts in their schedules this morning, and that all of them are deeply interested in what you are going to say, what the others have said, and all of them will study the record that is being made this morning.

I guess Senator Randolph did point out that the committee, this subcommittee, will have to stop its hearings at 11:30 and for that reason we urge you to speak extemporaneously from your statement and as briefly as you can and get the message across to us.

We will put your entire statement in the record.

STATEMENT OF JOSEPH L. COHEN, ESQ., IMMEDIATE PAST PRESIDENT OF UNITED CEREBRAL PALSY OF PENNSYLVANIA AND FORMER CHAIRMAN OF PENNSYLVANIA DEVELOPMENTAL DISABILITIES COUNCIL, UNITED CEREBRAL PALSY ASSOCIATION, HARRISBURG, PA.; ACCOMPANIED BY JAMES STEARNS, MEMBER, UNITED CEREBRAL PALSY ASSOCIATION GOVERNMENTAL ACTIVITIES COMMITTEE AND MEMBER OF THE NATIONAL ADVISORY COUNCIL ON DEVELOPMENTAL DISABILITIES, AND E. CLARKE ROSS, DIRECTOR, GOVERNMENTAL ACTIVITIES OFFICE OF UNITED CEREBRAL PALSY ASSOCIATION

Mr. COHEN. Thank you, Senator.

My name is Joseph Cohen, and I represent the United Cerebral Palsy Association.

On my right is James Stearns, who is a consumer member of the National Advisory Council on Developmental Disabilities and on my left is E. Clarke Ross, Director of the UCPA Governmental Activities Office.

My remarks will be addressed to four of the six points that we have outlined on page 1 of our testimony: the definition of developmental disabilities, planning and coordinating, viability of the seed grant concept, and the success and priority of advocacy.

United Cerebral Palsy Association believes that the developmental disabilities population, because of its unique problems, justifies its existence as a separate category, and the developmental disabilities program as such is justified by that act.

Persons with severe disabilities which occur in early life have substantial difficulties compensating for their disabilities because of the lack of prior experiences of normal growth in development; and the effects of these deprivations tend to stay with them throughout their lives.

Because of them, and because of the attendant problems they create, persons with developmental disabilities require a comprehensive system of delivery of services relating to the individual, the family, and community.

Our view is that the curve system of delivery of services really does not accommodate persons with developmental disabilities. The reason for this basically is the fact that current delivery systems are based on age and income, and they are not really based upon the needs of the individuals involved.

There is one aspect of developmental disabilities that I think it is important to emphasize. Because of the nature of developmental disabilities, many persons have experienced discrimination which has had an adverse impact upon the quality of their lives and upon the chances that ordinary persons can reasonably expect to have in society.

With regard to the definition of developmental disabilities, we feel generally that the definition should emphasize the functional problems that persons have rather than the diagnostic categorical behavior.

We realize that this is not a closed question, however, and there may be appropriate reasons for retaining diagnostic labels in certain situations. However, when we speak of the delivery of services, we feel that diagnostic labeling is inappropriate. Perhaps in the area of planning and medical research, diagnostic labeling certainly is appropriate, but on the delivery level, we feel that the functional problems that people have are the problems that should be addressed, and they should not depend upon the diagnostic label of the particular disability.

I would indicate that persons with severe developmental disabilities require a multiplicity of comprehensive services. However, the current delivery system is generally dominated either by age limitations, income limitations, or professional credentialing. This orientation of generic services results in gaps in the delivery system of services and requires some mechanism for coordinating services so that these gaps do not appear.

We think the concept of developmental disabilities is a valid and viable concept because it has focused attention on function of problems rather than diagnostic labels.

The fact that we have a developmental disabilities program has led to several beneficial results on the Federal and State level.

We are convinced, for example, that the housing development and community—pardon me, the Housing and Community Development Act would never have earmarked services for persons with developmental disabilities without the existence of the Developmental Disabilities Act.

Likewise, the HEW, Social Services Program Review Guidelines would never have focused on persons with developmental disabilities without the existence of the Developmental Disabilities Act.

Services have been expanded at State and local levels because of the Developmental Disabilities Act and the Developmental Disabilities Office within DHEW, and Federal generic services have recognized the unique needs of persons with developmental disabilities.

We feel on a State level that developmental disabilities planning efforts have proved successful in increasing services for persons with developmental disabilities delivered by other service providers. We do not believe that these service providers would have outreached to the developmental disabilities population without the existence of the developmental disabilities program.

I think it is important to keep in mind that the developmental disabilities program is designed to serve consumers, and that persons with developmental disabilities need a certain array of services. I think it is with this in mind that the Developmental Disabilities Act has mandated that the State councils have one-third consumers.

We would like to amend that to require that of the one-third consumers, one-half of them should be persons with developmental disabilities and not their surrogates, because we believe that this is the only way that recommendations, based on personal experience, get to the appropriate level of consideration.

Finally, I would think it is important to concentrate on the protection and advocacy program.

The reason for this is, as I have stated before, that persons with developmental disabilities tend to be treated not even as second-class citizens, but somewhere below that level.

It is necessary that the rights that have been established in the developmental disabilities legislation for developmentally disabled people have a viable mechanism by which they can be realized. Protection and advocacy are not only necessary to assure the people with developmental disabilities get adequate services which they otherwise might not get, but it is also important that their rights in society, apart from the service delivery system, be recognized and protected. This is all that I have to say at this point, Senator.

[Whereupon, Senator Stafford assumed the Chair.]

Senator STAFFORD. Mr. Cohen, for the subcommittee, we are grateful to you for coming in with your associates this morning and giving us your advice and counsel as we oversee the program.

In view of our time constraints, I have a question which I am going to turn over to you in writing, for response at your earliest convenience to the subcommitte, in writing, and with that, unless your associates have something they wish to say, we will call the next witness.

[The prepared statemen of Mr. Cohen and information referred to follows:]

STATEMENT

RESPECTFULLY SUBMITTED TO THE

SUBCOMMITTEE ON THE HANDICAPPED

OF THE SENATE COMMITTEE ON

HUMAN RESOURCES

ON

OVERSIGHT OF THE "DEVELOPMENTALLY

DISABLED ASSISTANCE AND BILL OF

RIGHTS ACT"

ON BEHALF OF

UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

THE CHESTER ARTHUR BUILDING

425 "EYE" STREET N.W., SUITE 141

WASHINGTON, D.C. 20001

MARCH 1977

U.C.P.A. Governmental Activities Office Washington, D.C.

INTRODUCTION

Joseph L. Cohen, Esq., is the immediate past president of United Cerebral Palsy of Pennsylvania (1974-1976), a member of United Cerebral Palsy Associations, Inc.Consumer Activities Committee (1975-1977) and Legal Advocacy Committee (1975-1977). Mr. Cohen is former chairman of the Pennsylvania Developmental Disabilities Council (1970-1971) and former chairman of that Council's advocacy committee (1972-1973). During this past year Mr. Cohen served on the Pennsylvania Governor's Planning Council for the White House Conference on Handicapped Individuals.

Accompanying Mr. Cohen is James Stearns, At - Large Member of UCPA's Governmental Activities Committee and Consumer Member of the National Advisory Council on Developmental Disabilities, and E. Clarke Ross, Director, UCPA Governmental Activities Office.

United Cerebral Palsy Associations' statement addresses the following subject issues:

(1) The Definition of "Developmental Disability"

(2) Planning and Coordinating Without Responsibility: Does It Work?

(3) Viability of the Seed Grant Concept

(4) The Success and Priority of Advocacy

(5) National Advisory Council Ideas

(6) Appendix One: UCPA Affiliate Utilization of State DD Funds, 1976

UCPA believes that the developmental disabilities population has certain unique characteristics which justify the existence of a separate categorical program. These persons, whose severe disability occurs early in life, have substantial difficulty compensating for their disabilities because they lack prior experiences of normal growth and development. These persons require a multiplicity of comprehensive services requiring individual, family, and community attention. The current service delivery system is generally dominated either by age limitations, income limitations, or professional credentialling -- this target population does not fit into existing generic service systems. Because of the nature of their disability, many persons who are developmentally disabled have experienced discrimination which diminishes their quality of life.

THE DEFINITION OF "DEVELOPMENTAL DISABILITY"

UCPA feels it would be premature to attempt a full-scale emendation of the current definition of "developmental disability" prior to completion of the definitional study mandated by Section 301 of P.L. 94-103; however, we do have a history of recommendations on the issue.

- Previous UCPA Proposals

Our 1973 Senate Subcommittee on the Handicapped testimony on the Developmental Disabilities Act recommended that:

> "A Developmental Disability means a disability which (1) is attributable to a physical and/or a mental impairment, (2) originates before the

(2)

individual attains the age eighteen and has continued or can be expected to continue indefinately, and (3) constitutes a severe handicap to substantial, normal activities."

Our 1976 Senate Subcommittee on the Handicapped testimony on the Rehabilitation Act of 1973 suggested that:

"Severely disabled persons are those individuals who have a multiplicity of disabling conditions which seriously interfere with their independent living and impair the development of self-care skills."

- Comment on the Easter Seals Proposal

On March 2, 1977, our sister agency, the National Easter Seal Society for Crippled Children and Adults, recommended the following definition of "developmental disability:"

"A developmentally disabled person is one with a physical or mental condition, originating before age 18 which is not responsive to treatment, which therefore can be expected to exist during the life of the individual, and which leads (or has led) to functional deficits which substantially interfere with the individual's ability to acquire normal skills and knowledge, to engage in competitive employment, or to manage his own affairs without assistance."

The Easter Seal Society further stated that "This definition makes no reference to a medically determined impairment or to a category of individuals. It is not an oversight on our part. It is only through an anaylsis of one's functioning ability that we can determine whether or not a person is disabled."

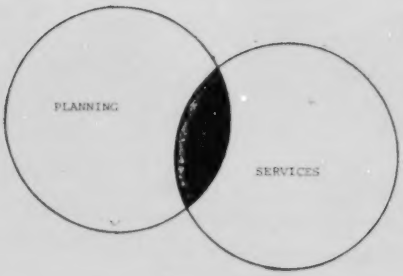
We believe that the recommended UCPA and Easter Seal definitions are most compatible, and we believe the intent underlying both -- the central focus upon functional disability -- is identical. We do object to the Easter Seal emphasis upon "treatment" as both a narrow and paternalistic concept of service provision, and we would like to see greater focus on the concept of multiplicity of disabling conditions; all other suggestions are identical to those of UCPA.

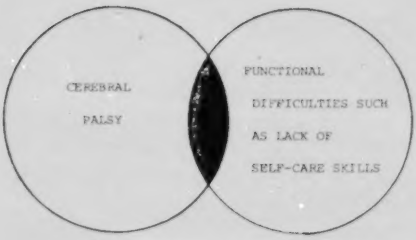
UCPA believes the multiplicity issue is quite important. The President's Committee on Mental Retardation, in its February,1975 study, documented that the following disabilities tend to occur as secondary disabilities in persons with mental retardation: ambulation, 32.4%; upper limbs, gross motor, 34.2%; Upper limbs, fine motor, 34.9%; speech, 33.4%; hearing, 11.5%; vision, 20.9%; seizuers, 15.1% and behavior and emotional disorders, 35.7%. This population which we term "developmentally disabled" is characterized by factors of severity and multiplicity.

- A Possible New Definitional Approach

A fundamental problem in attempting to define the developmentally disabled population is the act's dual focus as an instrument for both planning and service delivery. The planning function necessitates a fairly broad approach to the larger population; service delivery, on the other hand, demands a considerably narrower focus, in which specific functional difficulties and programmatic requirements are delineated. One possible method of dealing with this situation is to develop specific definitional criteria for each of the act's two major components - planning and service; a categorically-based definition for planning and a functionally-based definition for services. Such an approach could be conceptualized as follows:

(3)





"Planning"and "Coordination" bodies must continually distinguish between relatively small categorically-determined populations (such as individuals with cerebral palsy) and a much larger group of people with specific functional problems (e.g., those who use wheelchairs and require attendant care to start and end the day) whose number may include many individuals whose functional problems are not the result of cerebral palsy. While there are of course, areas of overlap between functional and categorical definitions, and between planning and service delivery activities (cf. shaded areas of diagrams above), these comparatively narrow interfaces can by no means be said to reflect the full universe of needs and problems, nor accurately depict all the types of individuals requiring federal services. In order to adequately characterize the types of planning and services needed -- and the population(s) to which they should be provided -- government must begin to consider new methods for defining these issues, and must look beyond that limited area in which need and population (however inadequately defined) appear to coincide.

We believe this concept warrants further subcommittee inquiry.

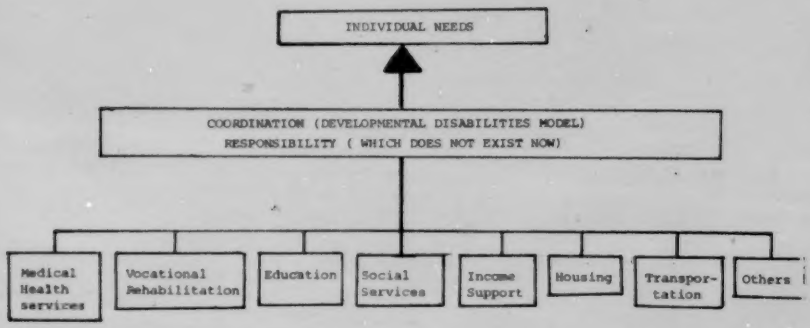
91-852 O - 77 - 9

(4)

PLANNING AND COORDINATING WITHOUT RESPONSIBILITY: DOES IT WORK?

Persons with severe developmental disabilities require a multiplicity of comprehensive services. The current service delivery system is generally dominated either by age limitations, income limitations, or professional credentialling. This single orientation of generic services results in gaps in the delivery of services, and requires some mechanism for coordinating services.

The conceptual basis for the Developmental Disabilities Act as a linkage tool can be articulated as follows:



UCPA sincerely believes that the DD program is a rational approach to planning specific services across service delivery system lines. Program performance is a difficult requirement when one looks at the coordination -- planning process. UCPA is convinced that the "Housing and Community Development Act" would never have earmarked services for persons with developmental disabilities without existence of the DD Act. We are convinced that HEW Social Services program review guidelines would never have focused on persons with developmental disabilities without the existence of the DD Act. We are certain the Medicaid Intermediate Care Facility program would have remained restricted to the mentally retarded without the DD Act. Services have been expanded at state and local levels because of the DD Act and the Developmental Disabilities Office within DHEW, federal generic services have recognized the unique needs of persons with developmental disabilities.

State DD planning efforts have proved successful in increasing services for persons with developmental disabilities delivered by other service providers. These providers would not have outreached to the developmentally disabled population without the existence of the DD program. Some examples might prove enlightening:

- As an outcome of a DD-funded low-incidence outreach program, persons with developmental disabilities received Supplemental Security Income (SSI) and Social Services (Title XX) benefits. (Illinois).

- As an outcome of a DD-funded independent living housing project for mentally alert, severely physically disabled persons, the Illinois State Housing Finance Agency is now planning services for persons with developmental disabilities.

- A specialized 48-bed residence for the severely disabled, has been constructed with DD funds. Operational funds are obtained from non-DD monies and, as an outcome of this demonstration, the Minnesota State Housing Finance Agency has developed specialized housing for persons with disabilities.

Congress should be realistic in its expectations regarding coordination and planning, recognizing that state DD agencies and councils have no responsibility for the provision of services. As a result of this lack of legal responsibility, many state DD programs have failed adequately to plan and coordinate services. Some examples --

- Although the New York State Department of Mental Hygiene has launched a multimillion dollar deinstitutionalization and community residential placement program, the state DD Council, primarily concerned with the allocation of its grant monies, has had no meaningful input into or influence upon this program trend.

- The Minnesota DD program has focused so exclusively on the mentally retarded that a major state legislative effort is underway to establish an Office of Special Services for the Severely Handicapped, to concentrate on the needs of severely physically disabled individuals.

- A feeling persists that the Michigan DD program is becoming more and more bureaucratic, more and more a paper planning process with beautiful documents sitting on the book self, and less and less sensitivity and responsiveness to the individual with a developmental disability. This sentiment has been expressed by numerous other state UCPA chapters. These organizations firmly believe that demonstration funds are essential in the DD program and that the focus on planning is destroying the service delivery aspect of the program.

- Consumer Involvement: Techniques for Increased Responsiveness

UCPA believes that adequate consumer involvement will increase the responsiveness of state DD programs. In our own organization we are responding to the demand by consumers for power equalization. Unfortunately, state DD Councils do not reflect adequate consumer involvement. In a study conducted by the Developmental Disabilities Technical Assistance System (1975), the majority of State DD Council members were middle-aged, white, male, and largely parents of persons who are mentally retarded.

UCPA recommends that Section 137 (a) of the act be amended to add to the current one-third consumer representation requirement that "at least one-half of this one-third be persons who are themselves developmentally disabled."

VIABILITITY OF THE SEED GRANT CONCEPT

An underlying assumption of the Developmental Disabilities Act is the value

of the so-called "seed grant concept," whereby the government supplies a grant to an agency to initiate the start-up or expansion of a program. The government then expects the grantee to find operational support when the initiation stage terminates. This funding approach has been a primary mechanism for serving persons with developmental disabilities through state programs; UCPA has encountered mixed success with this approach.

- The Hartford Connecticut Experience

United Cerebral Palsy Association of Greater Hartford has been in existence since 1949. For 23 years, the program fluctuated between solvency and bankruptcy as it operated a pre-school for multiply handicapped children and a very small summer camp program. As of 1971-1972, its budget was $30,000, not including a long-standing deficit. United Cerebral Palsy Association of Greater Hartford faced dis-affiliation and disassociation from the national association.

In 1971, funding for direct service programs serving the developmentally disabled became available from the Connecticut Developmental Disabilities Council. United Cerebral Palsy Association of Greater Hartford applied for, and received, a three-year grant totalling $113,683 to develop Social and Recreational Services for the Severely and Multiply Handicapped Adult. With seed money from the DD Council that affiliate implemented a program serving people ineligible for / unable to benefit from, other types of programs, whether these were therapy, schooling, or vocational in nature In three years the caseload increased from 25 people to nearly 300 families. UCPA programs became recognized as one of the most active in New England, and have been a model for other UCPA affiliates. UCPA has become recognized as a viable and important community service thereby eliminating its deficits and increasing its budget to nearly $300,000. As of July 1, 1975, the affiliate has been operating independent of DD Council funding, without curtailing services, and is looking forward to developing new services for persons with cerebral palsy and other developmental disabilities.

UCPA of Greater Hartford's DD grant not only provided funding for direct services but also provided leverage to tap other funding sources. DD funding established the affiliate's community identity, and as a result it was able to increase personal contributions, foundations, grants, and utilize other resources (e.g. Urban Mass Transportation Act, Work Incentive, Housing and Community Development Act).

- The Edison, New Jersey Experience

From UCPA of Middlesex County comes the following statement:

"As far as Middlesex County is concerned, I can add without equivocation that the DDSA funding has directly helped our Agency better serve adult clients of our center. Thanks to "seed money" initially provided through a two year funding grant from our State's Developmental Disability Program, our Work Activity Center has grown and developed in one of the most comprehensive Work Activity Centers in the State of New Jersey. We now have 30 clients, who are performing well beyond expectation. Thanks to DD funding severely disabled young men and women have a chance for a productive and meaningful life."

The Work Activity Center participants operate under a contract with the Revlon Corporation, five days a week, five and one-half hours a day. All individuals involved in the Center have never worked previously. The Center is now financially independent from DD support.

(7)

- The Baltimore, Maryland Experience

United Cerebral Palsy of Central Maryland has been highly successful in establishing programs with DD funds and continuing them with other sources of revenue. For example:

(1) Social Service Grant 1973 - 1975 $43,500.00

"This project has had perhaps the biggest single impact on our affiliate's internal development within recent years. Not only did the individuals hired begin working with families of cerebral palsied children, teens and adults, but the program freed staff time for the development of new programs and a stress on social and recreational goals. Our entire emphasis on adult education, socialization and recreation to date is in direct relationsjip to this grant. Two of the original staff now fill high administrative program planning positions while the social service component still remains a part of our child oriented programs even though DD funding has expired."

(2) Camp New Horizon 1975 - 1976 $20,500.00

"This program meant that our affiliate began for the first time an expansion to year round services, extended parent day relief during the hot summer months and gave children with cerebral palsy an opportunity to enjoy healthy outdoor fun and recreation for its own sake. Although DD funding has expired, UCP/CM will continue and in fact, expand this program. In 1975, 50 children with cerebral palsy participated; in 1976 100 children attended the camp (30 from Rosewood); and in 1977, 150 children will be accepted. "

(3) Essex Development Center 1975 $13,000.00

"Initially, this development program included 16 severely disabled children and DD money went primarily toward capital equipment. This center was necessary due to a waiting list and the lack of a day center in Eastern Baltimore County. Today this development center remains in operation and has an enrollment of 30 children."

(4) Respite Care 1976 - 1977 $12,000.00

"This program will have given parents approximately 200 days of emergency, weekend and vacation placement and care for their disabled family member outside the home by 1977. UCP/CM is the only private agency in the Baltimore Metropolitan area offering this program to physically disabled children. "

- UCPA's Approach To DD Funding Philosophy

Without a doubt Developmental Disabilities funds have served as the major incentive to establish and expand services to persons with cerebral palsy throughout the nation. The seed grant concept works: programs can be established, demonstrated to succeed, and then be picked financially up elsewhere. For example:

(1) UCP of Illinois declared: "In our opinion the Developmental Disabilities program has been a godsend to Illinois."

(2) UCP of Panama City (Florida): "DD funds are the only monies available for the non-retarded cerebral palsy persons. Since many of our clients are non-retarded, this could really present a problem if the funds are no longer available." Most of the generic services in Florida, such as Medicaid and Social Services, as well as state initiated programs, are restricted to the mentally retarded.

(8)

(3) UCP of Lehigh Valley (Bethlehem, Pa.):

> "When the Developmental Disabilities Act was proposed and enacted by Congress, agencies who serve the mentally alert, severely handicapped were given hope for the first time. In the state of Pennsylvania, clients had to be retarded to "qualify" for funds; or be minimally handicapped to receive B.V.R. consideration. The Developmental Disabilities Act opened up a new horizon of possibilities for priority programs."

To present a candid and complete picture, it must be noted that the seed money concept has also frequently failed -- at the end of a three year DD grant many UCPA affiliates have not found adequate replacement funds and crises of program continuity have occurred. UCPA national is now exploring what factors contribute to the success or failure of seed grant approaches. We suggest that this is an area requiring Congressional and federal agency inquiry.

P.L. 94-103 altered the focus of the Developmental Disabilities program from its service orientation to its planning and advocacy functions; this change is reflected in the reduction of UCPA affiliates that received grants from 1972 to 1976. This trend will continue; however, it must be emphasized that there are communities and states throughout the nation where DD service funds are required. There is an appropriate role for service grants under the DD program; persons with cerebral palsy may not receive any service without the DD program.

The 1971 and 1972 information below was submitted in detail with UCPA's February 8, 1973 testimony on Developmental Disabilities before the Senate Subcommittee on the Handicapped. Figures for 1976 are detailed in Appendix One of this statement.

(1) UCPA Affiliates Receiving State DD Grants

1971	1971	24
	1972	56
	1976	35

(2) Total State DD Grant Funds Received By UCPA Affiliates

1971	$587,279
1972	1,718,055
1976	1,451,633

(3)

1971		1972		1976	
Transportation	7	Children Services	21	Children Services	15
Children Services	4	Adult Services	12	Adult Services	8
Additional Professional Staff	4	Home Services	9	Purchase Specialized Equipment	4
		Transportation	8	Transportation	3
		Sheltered Workshops/ Work Activity Centers	8	Home Services	3

(9)

- Inadequate Funding

Though programs have been successfully launched, the DD program has only scratched the surface in meeting needs. For example, the Illinois Developmental Disabilities Council estimates that the state only serves 10-15% of the unmet needs identified for persons with developmental disabilities from all public and private sources of funds. Higher authorization levels in the state formula grant is required now.

- Ongoing Service Needs

There are still some program needs which no current service provider will fund. These areas require continual DD state financial support if the service is to be provided at all. Some examples:

(1) A client equipment bank in Illinois permits the purchase of special adaptative equipment to allow persons with severe physical disabilities to live more independently.

(2) Specialized dentistry programs for persons with developmental disabilities in many states throughout the nation (e.g. New Jersey and Iowa).

(3) Centralized Optometric Center for persons with developmental disabilities in Maryland.

(4) Respite care programs providing emergency, weekend, and vacation placements (such as that in Maryland).

(5) Life Skills and Transitional Training program in Lehigh Valley, Pennsylvania Life skills are defined as those skills necessary to function in ones place of residence, i.e, cooking, shopping, etc. Forty-eight severely disabled persons were served by a DD grant -- they were too severely involved with low employment potential for DVR,and no new Title XX contracts are being made in the state because of the annual financial ceiling and the overwhelming demands of many groups in need.

- Construction of a comprehensive therapeutic, education, and rehabilitation center for severely disabled persons in Bethlehem, Pennsylvania.

THE SUCCESS AND PRIORITY OF ADVOCACY

One of the major accomplishments of the Developmental Disabilities program at national, state, and local levels has been the development of creative and varied approaches to systematic advocacy for persons with developmental disabilities.

Because of the nature of their disability, many persons have experienced discrimination which diminishes their quality of life; these persons require an advocacy mechanism to guarantee respect for their rights and generate change. This frequently can be accomplished systematically by state and federal DD program attempts to change the basic mandates and priorities of generic agencies which frequently neglect persons with developmental disabilities.

Many DD programs have initiated a variety of advocacy approaches which are worthy of mention:

- Through the joint financing of the Developmental Disabilities Office (DDO), The National Institute of Mental Health (NIMH), and the Bureau of Education

for the Handicapped (BEH), United Cerebral Palsy Associations, Inc. has sponsored a five-year demonstration project establishing and maintaining different advocacy programs in Palo Alto, California; New York City; Milwaukee, Wisconsin; Kansas City, Missouri; Providence, Rhode Island; and Springfield, Illinois.

UCPA defines advocacy as ensuring persons who are disabled their rights to appropriate services. A major reason for the success of UCPA's advocacy programs is that they have brought consumers into an environment of peer exchange with parents, volunteers, and agency professionals.

- The State of Maryland has launched a Developmental Disability Law Clinic which has concentrated to date on liability concerns, guardianship concerns, legal advocacy, and statutory interpretation and research.

- The Connecticut DD program has supported the UCPA of Connecticut Respond (Resource To Encourage Services to Provide for the Ongoing Needs of the Disabled) program, which is primarily an information, referral, and ombudsman program for 375 severely disabled persons in the sixteen-town greater New Haven area.

The Protection and Advocacy System mandated under Section 113 should, we believe, become a more centralized focus of the DD Act and program. UCPA is anxiously awaiting the state plans which will implement P & A systems in October, 1977. If the necessary incentives to states are to be developed, and if P & A systems are meaningfully to influence the quality of service to persons with developmental disabilities, the current $3 million authorization must be drastically increased with a minimum state allotment requirement. We will have a better idea of the minimal necessary federal allotment when state P & A plans are submitted and analyzed this fall.

NATIONAL ADVISORY COUNCIL IDEAS

A great deal of attention has focused on the role, performance, and responsibilities of the National Advisory Council on Developmental Disabilities (NAC/DD) as required by Section 108 of the Act.

As a statement of philosophy, UCPA firmly believes in the necessity of private citizen advisory panels to monitor and influence operation of governmental agencies. We believe in the principles of open government, participatory management of publicly operated programs, and client focused organizations; with regard to the NAC/DD this requires meaningful input of parents with disabled children and persons who are themselves disabled.

Although the NAC/DD is mandated and restricted by Section 108 of the Developmental Disabilities Act, UCPA has slowly come to the opinion that the model provided by the State Planning Councils, as mandated by Section 137 of the Act, is a more appropriate role for the NAC/DD to fill. Specific examples of this would be:

- The development of an annual national developmental disabilities plan outlining specific goals and priorities for the program.

- The provision of adequate and independent staff directly responsible to the Council.

- The guarantee of adequate representation from each disability group specified in federal statute. In this regard, we firmly advocate

that at least 1/3 of the Council membership be consumers and that at least 1/2 of this 1/3 be persons who are themselves developmentally disabled.

- The provision of specialized training of NAC/DD members to increase their effectiveness and sophistication.

Many state councils have been very effective in improving the service delivery system in meeting the needs of persons with developmental disabilities. UCPA believes that NAC/DD could be equally effective if their authority was specific in nature, if their membership was adequately representative of the field, and if their resources are equal to the task.

APPENDIX ONE:

UNITED CEREBRAL PALSY ASSOCIATIONS, INC.
AFFILIATE UTILIZATION OF STATE DEVELOPMENTAL DISABILITIES FUNDS, 1976

AFFILIATE	DD GRANT	PURPOSE OF DD GRANT
Gadsden & Northeast, Alabama	$15,271	Educational, recreational, therapeutic & developmental services
Central, Arizona	7,995	Speech, physical & occupational therapy expansion
Orange County, California	30,000	Infant project transdisciplinary team expansion (O.T.P.T., nurse)
Denver, Colorado	6,720	"Project Prevention" Film
Delaware	8,423	Daily activities program
Florida	29,757	Statewide program
Miami, Florida	30,336	"Infant stimulation (exterior sensory learning environment)
Northwest, Florida	25,465	To purchase Mancino therapeutic chairs
Panama City, Florida	26,013	Kindergarten, nursery and infant intervention program
Rome & Northeast, Georgia	35,455	Construction for Work Activity Center
Black Hawk Region, Illinois	75,000	Day care for adults; purchase & provision of transportation and case finding information & referral
Chicago, Illinois	309,410	Adult developmental services
Delaware County, Indiana	1,911	Maintenance, salaries, gas for bus
Iowa	17,928	Consumer Conference
Cedar Rapids, Iowa	500	Day Care Program
Blue Grass, Kentucky	41,188	Parent-infant Program
Northern, Kentucky	5,395	Physical, speech and occupational therapy
Northeastern, Maine	26,000	Infant Development

AFFILIATE	DD GRANT	PURPOSE OF DD GRANT
Central, Maryland	$ 7,000	Respite Care Program
Prince Georges County, Md.	9,600	Home Therapy Program
Southeast, Nebraska	22,540	Information and referral
Cumberland, New Jersey	32,978	Home services& early intervention
Capital District, New York	123,633	Expansion of services
Finger Lake, New York	14,000	Physical therapist; neurological equipment, evaluations & purchase
Niagara County, New York	3,950	Communications - bliss symbolics
Schenectady, New York	19,056	Infant Stimulation Program
Sullivan County, New York	35,120	Rehabilitative & remedial programming for DD Children
Tri-Counties, New York	18,316	Home Management Program for DD Children
Western, New York	36,745	Speech Program for Multiply-Handicapped Child
Capital Area, Pennsylvania	6,093	Seminar - (30 hr. College cours Human Sexuality
Sioux Empire, South Dakota	95,034	Establish Community Living Cent purchase & operation of van
Dallas, Texas	16,823	Identification of DD individua nursing homes needing services
Texas Gulf Coast, Texas	28,651	Life enrichment and adaptive s training
Benton & Franklin Counties, Wash.	90,439	Client Program Services
King County, Washington	198,868	Life enrichment day care facili and work activity program

TOTALS

35 UCPA Affiliates receiving DD Funds	$1,451,633 Total 1976 DD Income	Children services: 15 Adult Services: 8 Purchase specialized equipment 4 Transportation 3 Home services 3 Residential services 2 Public education 2 Information & referral 2 Respite care 1 Consumer Development 1 Organization Development 1
276 Total UCPA Affiliates	$44 million total UCPA annual expenditure	
	$16 million total UCPA annual third party grants and contracts	

PREPARED BY:

Patricia Boulware
Administrative Assistant

E. Clarke Ross
Director

UCPA GOVERNMENTAL ACTIVITIES OFFICE

UNITED CEREBRAL PALSY ASSOCIATIONS, INC. • 66 EAST 34th STREET • NEW YORK, NEW YORK 10016
(212) 889-6655

REPLY TO:

April 8, 1977

UCPA Governmental Activities Office
Chester Arthur Building
Suite 141
425 I Street N.W.
Washington, D. C. 20001
(202) 638-6169

Honorable Jennings Randolph, Chairman
Senate Subcommittee on the Handicapped
10-B Russell Senate Office Building
Washington, D. C. 20510

Dear Senator Randolph:

In reply to your questions of April 1, 1977, please find enclosed United Cerebral Palsy Associations' responses. UCPA appreciates the Subcommittee's overriding concerns with equal employment opportunities for persons with disabilities.

Sincerely,

E. Clarke Ross

E. Clarke Ross, Director
UCPA Governmental Activities Office

Enclosure: 1

ECR:gw

LEONARD H. GOLDENSON, CHAIRMAN OF THE BOARD · JACK HAUSMAN, VICE CHAIRMAN · GEORGE A. SCHWEIZER JR. ESQ., VICE CHAIRMAN · WARREN F. BOZO, PRESIDENT · GILLIAM GERONDELIS, M.D., VICE PRESIDENT MEDICAL AFFAIRS · EARL N. CUMERO, EXECUTIVE DIRECTOR

SUPPLEMENTAL MATERIAL

SUBMITTED AT THE REQUEST OF THE

SENATE SUBCOMMITTEE ON THE HANDICAPPED,

COMMITTEE ON HUMAN RESOURCES

ON

QUESTIONS RELATING TO OVERSIGHT OF THE

DEVELOPMENTAL DISABILITIES ACT

ON BEHALF OF

UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

THE CHESTER ARTHUR BUILDING
425 "Eye" Street, N.W., Suite 141
Washington, D. C. 20001

April 1977

Question: You state that United Cerebral Palsy is now exploring the reasons that contribute to the success or failure of seed grant approaches. Do you have any preliminary findings?

A November 4, 1975 Gallup poll of public attitudes toward the disbursement of funds by voluntary health organizations and by government agencies revealed that, by more than a 3:1 margin, respondents believed that more of each dollar is spent on direct service delivery by voluntary than by government agencies. Clearly, then, the public perception of groups such as UCPA is that of effective and highly visible providers of services to those in need.

An increasing proportion of financial support to UCPA affiliates comes from public tax monies through federal, state, or local governmental agecies in the form of grants, purchase-of-service contracts, and other third-party resources (Last year, out of $44 million in expenditures, over $16 million was derived from public agencies). Much of this money is in the form of seed grants.

We are greatly concerned with the appropriateness and viability of this funding approach. Our experience in working with roughly 300 state and community organizations (UCPA affiliates) indicates the following problems with continuing programs initiated with short-term seed grants:

1) Limited Private Fundraising Capacity

There is a very real limit to the fundraising capabilities of voluntary agencies and communities. Our experience leads us to conclude that one can expect to raise no more than a 5 to 10% increase annually from independent fundraising, and no more than a 2% increase annually from United Fund support. If a local community agency has doubled its budget through a public grant, it is unlikely that it will be able to double its private fundraising efforts in a two or three year period.

2) Need For Diversified Funding

Those community agencies most successful in continuing services inititally funded by seed grants usually have diversified funding sources. Not only are their private fundraising efforts firmly based and growing annually, but they have been able to integrate into a single program public sources of funds in a rational and sophisticated manner. For example, UCPA of Pittsburgh's supervised apartment program is funded by a combination of Vocational Rehabilitation, Developmental Disabilities, Urban Mass Transportation, HUD Section 8 rental assistance, Title XX Social Services, Title XVI Supplemental Security Income, private foundation support, and UCPA privately raised funds. Each of these funding sources is specifically targeted to a particular program component; if any one of these components is not available, the entire housing program is in jeopardy.

3) Governmental Red Tape and Case Flow Difficulties

With those grants which UCPA, Inc. (the national organization) has received directly from the federal government, we have experienced no delays or cash flow difficulties. However, cash flow is a substantial problem when dealing with state and local government agencies. Many of our affiliates have had to resort to borrowing operating funds at commercial bank interest rates in order to provide services until state or local government funding was forwarded. We now advise all our affiliates to budget based on a three-month delay in payment, even though funding contracts are signed and binding.

4) Conflicting Governmental Rules

As has been stated, diversified funding is a key to adequate and stable financing of services; however, each state and local government agency has its own rules and regulations governing disbursement of funds. Frequently, these rules contradict one another. Frequently, separate and difficult accounting procedures are required. Seldom do these agencies ever attempt to simply or coordinate these funding patterns. Many of these agencies serve different target populations. For example, many state and county mental retardation agencies will only serve the ambulatory mentally retarded so that financial support is only available to a small number of clients under limited circumstances. The result is increased administrative costs or unavailability of funds to agencies such as UCPA affiliates.

5) Strong Board of Directors

To be successful and stable financially, a local organization must have a strong, dedicated, and diverse board of directors. Voluntary agencies require a great many skills and resources in order to be successful. Without a strong board, the necessary community visability may be lacking.

Likewise, a strong Professional Services Program Committee of the board is required. These committees largely determine an organization's program priorities. Adequate needs assessment will determine community programs; weak, unnecessary, or duplicative services can be terminated. Appropriate program budgeting techniques can be introduced into the normal business procedures of the organization. Without such a committee, many of these activities are never undertaken.

- Conclusion

UCPA firmly believes that public funding agencies should launch a thorough examination of the seed grant concept. Although many of our chapters have been very successful with this approach, many others have failed. Often hopes are inspired which are not fulfilled. Although UCPA is a federation of independently organized state and community organizations, as part of the affiliation agreement we are encouraging affiliates to become accredited by the Accreditation Council on Services for the Mentally Retarded and Developmentally Disabled (ACS/MR & DD) of the Joint Commission on Accreditation of Hospitals (JCAH). In this way, we hope to increase the financial and managment skills of our members so they can deal more adequately with the seed grant dilemma.

(3)

Question: Please provide a listing of any federal grants your organization has and a description of the activities conducted under such grant.

United Cerebral Palsy Associations believes in maintaining an adequate balance between public and private financial support for our activities. In his introductory remarks to the 1976 Annual Report, UCPA President Warren Beer, stated that "we must be cautious about the trend toward governmental funding of our programs and services ... As a voluntary agency, we must seek community support more aggressively and effectively to underwrite our basic, ongoing programs as we take advantage of the opportunities for government funding to add new programs and services for our clientele." UCPA believes federal programs play the instrumental dual roles of catalyst and demonstrator of unique approaches to solving needs of persons with developmental disabilities.

UCPA, Inc. (the national organization) has an annual income in excess of $3 million. We currently have only two federal grants; both of these grants will terminate on June 30, 1977:

- National Advocacy Demonstration Grant

Jointly funded by the Bureau of Education for the Handicapped, the Developmental Disabilities Office, and the National Institute for Mental Health, the Project, supervised by BEH, awarded $182,544 to UCPA for the period July 1, 1976 to June 30, 1977.

The project has established model systems of advocacy in Palo Alto, California; New York (statewide); Milwaukee, Wisconsin; The Greater Kansas City area; Providence Rhode Island; and Illinois (statewide).

- National Infant Collaborative Project

Funded by the Bureau of Education for the Handicapped, the project awarded $200,000 to UCPA for the period July 1, 1976 to June 30, 1977.

The project has greatly enhanced our knowledge regarding early intervention and the delivery of services for atypical infants and their families. The project has established numerous new infant programs throughout the nation and has enabled replication of exemplary models of service. Fifty-four centers have participated in the project providing services to approximately 4000 families over the last six years.

Question: What percentage of your organization's employees are handicapped? Please provide breakdown of the percentage in professional positions and the percentage in clerical positions.

In 1975, United Cerebral Palsy Associations established, as a standing committee of the national board of directors, the Consumer Activities Committee. The Committee, staffed by disabled persons, is composed entirely of persons with

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disabilities, almost all of whom are disabled by cerebral palsy. The Committee's objectives are not only to increase the employment of disabled persons within UCPA, but equally important,to encourage more consumers to become active volunteers within the organization and to encourage employment and related affirmative action practices towards the disabled in government and private business. Many disabled persons desire employment in sectors of American life which are not primarily devoted to the cause of persons with disabilities. The following employee information will answer the inquiry:

Cateogry	Numbers	Percentage
Total UCPA, Inc. Employees	95	100%
a) includes part-time Employees		
b) 5 District Offices	(20)	(21%)
Total Disabled Employees		
a) All full time Employees	10	10%
b) Professional Employees	(5)	(5%)
c) Clerical Employees	(5)	(5%)

The District offices (New York, Atlanta, Chicago, Dallas, and San Francisco) are broken out because of the uniqueness of the jobs. These district persons travel from three to four weeks during each month, providing consultation to UCPA affiliates. The only disabled employee in the District offices was recently hired as the executive secretary of the California Developmental Disabilities Council.

Submitted By:

E. Clarke Ross, Director
UCPA Governmental Activities Office

Mr. STEARNS. Senator Stafford, if the committee would grant me just a moment.

Senator STAFFORD. Can you speak just a little louder?

Mr. STEARNS. Yes; I can.

The only thing I would say, Senator, is that we all recognize that you on the committee are going to have some hard decisions to make in the next year about this program. You are going to have to decide whether you renew the act as it is or with some modifications.

And it may be that this program will be reorganized.

I just have—I guess you would call it a plea, Senator, that all of your actions here legislatively be taken with the thought that I know the Senator from Vermont does have: what effect is this going to have on this part of the population? Not only on people like myself and Joe who make it through the system, but rather on those consumers who are coming up the pipeline.

If this committee will look at their needs and take into account what effect their actions are going to have on the people down there, I think it would be most helpful, because my fear is that there are problems with this act.

But it is on the right track and it is a very hard decision to make. It is a hard judgment to come into.

I would not want to see this very severely handicapped population left out. I hope that we can come to some agreement by which the rights and service delivery system are extended to this population.

I know you are under time constraints, sir.

Senator STAFFORD. Thank you very much.

I can assure you that this committee will do its best to look after the people who have developmental disabilities.

And with that, we express our appreciation to all three of you and the Chair will invite Susan C. Hillbrath to take the chair.

We are happy to have you here.

Let the record show that you are representing the American Occupational Therapy Organization of Governmental and Legal Affairs Staff here in Washington.

Have I got that right?

STATEMENT OF SUSAN C. HILLBRATH, OTR, AMERICAN OCCUPATIONAL THERAPY ASSOCIATION, GOVERNMENT AND LEGAL AFFAIRS DIVISION STAFF, ROCKVILLE, MD.; ACCOMPANIED BY ROSEMARY L. WILSON, ESQ., ASSISTANT DIRECTOR, GOVERNMENT AND LEGAL AFFAIRS DIVISION, AMERICAN OCCUPATIONAL THERAPY ASSOCIATION, INC.

Ms. HILLBRATH. Yes, that is right.

I am accompanied today by Rosemary Wilson, who is also with the Government and Legal Affairs Division.

We are pleased to participate in the subcommittee's examination of programs for individuals with developmental disabilities.

In the interest of time, I will not read our entire statement, but summarize.

Senator STAFFORD. Would you like your entire statement in the record?

Ms. HILLBRATH. Yes, sir, I would.

Senator STAFFORD. Without objection, we will put it in at the conclusion of your testimony.

Ms. HILLBRATH. Thank you.

For 60 years this association has represented independent health professionals who specialize in alleviating the suffering and increasing the independence and productivity of the aged, the physically or mentally disabled, and the economically or culturally disadvantaged.

Occupational therapists are among the few nonphysician health professionals who are trained in the rehabilitative, psychosocial, and developmental sciences.

They provide services in general and psychiatric hospitals, nursing homes, tuberculosis sanitoriums, community mental health and mental retardation centers, habilitation and rehabilitation agencies, home health settings, and public and private school systems.

One of the primary goals of occupational therapy is to assist individuals to realize their maximum developmental potential, and to minimize, if not eliminate, any restrictions on the individual's personal liberty. Occupational therapists and this association therefore support the goals of the Developmentally Disabled Assistance and Bill of Rights Act.

Our representative assembly has also mandated that the association and the 23,000 members which it represents, advocate the civil rights of all handicapped people.

It is because of our dedication to this purpose that we have an interest in the subcommittee's hearings today.

We would like to touch very briefly on some of the problems which occupational therapists and their clients have observed in various programs for the developmentally disabled.

First, public ignorance, indifference, or hostility toward the developmentally disabled continues to hamper full implementation of Federal incentives to promote deinstitutionalization or more appropriate institutionalization or treatment.

This problem is particularly severe for children who are official wards of the State, and for the adult developmentally disabled.

Second, State planning councils are not required to include providers of services to the developmentally disabled. The membership is usually composed of top-level agency administrators who are far removed from the daily realities of these programs, and of consumers who often are familiar with only one or two specific services.

Providers of these services, on the other hand, have a broad scope of experience with many programs because they deal with many agencies, many types of developmentally disabled clients, and provide a variety of services. Representation of providers who have daily contact with clients and broad experience with the multitude of State and Federal programs should be mandated on these State planning councils.

Third, current authorities for the transportation of the developmentally disabled appear to overlook the need to adapt vehicles to permit safe transportation of the severely disabled.

We recommend funding for adapting vehicles to meet these needs and we recommend that standards be developed which specify the

types of restraints or adaptations necessary for the safe transportation of the severely disabled.

And, finally, we strongly urge the consideration of a Federal program to encourage States to adopt laws which provide tax incentives or other benefits to encourage families to adopt handicapped children.

Many facilities for the developmentally disabled are, in reality, orphanages for children whom the public does not wish to acknowledge.

Families may be reluctant to adopt these children because they may not be able to support the costs of their therapeutic needs.

All handicapped children, regardless of their categorical designation—developmentally disabled, physically handicapped, emotionally disturbed, learning-disabled, and so forth—would benefit from a general incentive of this type.

Our detailed comments on these points are contained in our written statement.

The association appreciates this opportunity to share with the subcommittee our concerns about programs for the Nation's disabled citizens.

If you have any questions, I will be pleased to respond to them.

Senator STAFFORD. Well, thank you very much.

We really appreciate, all of us on the committee, your willingness to be here and help us.

Once again, in the constraints of time which the subcommittee is facing, we have a question which we will ask you to respond to in writing, rather than taking the time at the present time.

Does your associate have anything to add to what you have said?

Ms. WILSON. Just that we appreciate the opportunity to appear here. Our constituents have been informed of the type of hearing that you have been holding since the 95th Congress convened, and we are glad that you are undertaking oversight hearings of this type.

Senator STAFFORD. Thank you both very much.

[The prepared statement of Ms. Hillbrath and information referred to follows:]

The American Occupational Therapy Association, Inc.

STATEMENT OF THE AMERICAN OCCUPATIONAL THERAPY ASSOCIATION ON DEVELOPMENTAL DISABILITIES PROGRAMS*

Mr. Chairman and Members of the Subcommittee:

My name is Susan C. Hillbrath. I am a registered occupational therapist and am appearing on behalf of the American Occupational Therapy Association. We are pleased to participate in the Subcommittee's examination of programs for individuals with developmental disabilities.

For 60 years this Association has represented independent health professionals who specialize in alleviating the suffering and increasing the independence and productivity of the aged, the physically or mentally disabled, and the economically or culturally disadvantaged.

Occupational therapy practitioners are trained in curricula involving developmental psychology, anatomy, neurophysiology, and the social sciences. This training is followed by field work experience in areas such as psychiatry, rehabilitation, gerontology, and developmental disabilities.

Occupational therapists are among the few non-physician health professionals who are trained in the rehabilitative, psychosocial, and developmental sciences. They provide services in general and psychiatric hospitals, nursing homes, tuberculosis sanitoria, community mental health and mental retardation centers, habilitation and rehabilitation agencies, home health settings, and public and private school systems.

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*Presented by Susan C. Hillbrath, OTR, of the AOTA Government and Legal Affairs Division, before the Subcommittee on the Handicapped, Committee on Human Resources, United States Senate, March 31, 1977. Mrs. Hillbrath is accompanied by Rosemary L. Wilson, Esq., also of the AOTA Government and Legal Affairs Division.

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One of the primary goals of occupational therapy is to assist individuals to realize their maximum developmental potential, and to minimize, if not eliminate, any restrictions on the individual's personal liberty. Occupational therapists and this Association therefore support the goals of the Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103). Our Representative Assembly has also mandated that the Association and the 23,000 members which it represents, advocate the civil rights of all handicapped people. It is because of our dedication to this purpose that we have an interest in the Subcommittee's hearings today.

We would like to share with you some of the problems that occupational therapists and their clients have observed in various programs for the developmentally disabled. These are summarized below:

1. Public ignorance, indifference, or hostility towards the developmentally disabled continues to hamper full implementation of Federal incentives to promote deinstitutionalization or more appropriate institutionalization and treatment. This problem is particularly severe for children who are official wards of the state, and for the adult developmentally disabled.

2. State Planning Councils are not required to include providers of services to the developmentally disabled. The membership is usually composed of top-level agency administrators, who are far removed from the daily realities of these programs, and of consumers who often are familiar with only one or two specific services. Providers of these services, on the other hand, have a broad scope of experience with many programs because they deal with many agencies, many types of developmentally disabled clients, and provide a variety of services. Representation of providers who have daily contact with clients and broad experience with the multitude of state and Federal programs should be mandated on these State Planning Councils.

3. Current authorities for the transportation of the developmentally disabled appear to overlook the need to adapt vehicles to permit safe transportation of the severely disabled. We recommend funding for adapting vehicles to meet these needs, and we recommend that standards be developed which specify the types of restraints or adaptations necessary for the safe transportation of the severely disabled.

4. We strongly urge the consideration of a Federal program to encourage states to adopt laws which provide tax incentives or other benefits to encourage families to adopt handicapped children. Many facilities for the developmentally disabled are, in reality, orphanages for children whom the public does not wish to acknowledge. Families may be reluctant to adopt these children because they may not be able to support the costs of their therapeutic needs. All handicapped children, regardless of their categorical designation (developmentally disabled, physically handicapped, emotionally disturbed, learning disabled, etc.) would benefit from a general incentive of this type.

5. Although targeted programs are important to provide recognition and impetus in meeting the special health and treatment needs of Americans, their major drawback is that they tend to compartmentalize Federal programs. This results in a lack of program coordination. There are, at a minimum, six major public laws which can or do have a significant impact upon the treatment and needs of the developmentally disabled population. The existence of these highly targeted authorities often results in a maximum of red tape and a minimum of program efficiency. There must be greater program coordination -- rather than new legislation -- so that Federal health and treatment dollars will actually benefit the individuals they were intended to benefit. Many existing programs are capable

of meeting the currently unmet needs of the developmentally disabled, but only if these programs are coordinated.

Our detailed comments on these points follow.

I. INAPPROPRIATE INSTITUTIONALIZATION

In spite of efforts to discourage inappropriate institutionalization, the developmentally disabled are still victims of societal intolerance. Therapists in mental retardation facilities have encountered instances in which mildly or moderately mentally retarded children received sufficient treatment and training to permit them to return home and to develop their potential. Their parents, however, exercised their political or financial power and found a way to keep the children in the center, away from the family and neighborhood. In the case of children in these centers who are official wards of the state, the sheer weight of the judicial process can block their successful discharge to more appropriate settings.

In addition, it is not uncommon for society's outcasts -- such as orphans, children with multiple physical (but not mental) handicaps, children with emotional adjustment problems, or children who are socially and economically disadvantaged -- to be placed in mental retardation facilities, because they have been rejected everywhere else. This form of inappropriate institutionalization is devastating to the child intellectually as well as emotionally. Children with normal IQs can regress dramatically and actually learn to become retarded; they lose affect and become totally institutionalized.

Mental retardation facilities should be used only for the care and treatment of the mentally retarded. They must not be used as detention centers for children whom society has failed.

We realize that the Congress cannot legislate tolerance, but we urge that efforts continue to be made to break through this barrier of social rejection which results in improper institutionalization. We recommend that Congress require the closest possible working relationship between

the implementation of provisions of the Developmentally Disabled Bill of Rights (P.L. 94-103) and those of the Consumer Health Information law (P.L. 94-317). The public must be better informed regarding the potential of all disabled citizens if these barriers are to be eliminated.

Another group of developmentally disabled citizens who bear a special burden are the adult disabled. People often pay lip service to the "tragedy" of a retarded or autistic child, but when that child grows into an adult -- especially an elderly adult -- the adult's existence is no longer even acknowledged. Some organizations have tried to establish community group homes or halfway houses. As with the case of similar attempts to establish homes for children, the local citizens sometimes exercise their political and economic power to keep such homes out of their comfortable neighborhoods.

Without these halfway facilities, developmentally disabled adults must either remain virtually incarcerated in facilities from which they can derive no further therapeutic benefit, or they must go out into the community on their own, without supportive guidance or assistance. We believe that community group homes are a constructive, appropriate alternative to institutionalization and that the Congress should continue to encourage their establishment.

II. STATE PLANNING COUNCILS

Public Law 94-103 directs that State Planning Councils for services to the developmentally disabled be composed of representatives of state and local agencies, consumers of disabilities services, and groups "concerned with" services to the developmentally disabled. In practice, State Planning Councils are often composed of high-level administrators who have a broad programmatic viewpoint, and of consumers who have a highly individualized viewpoint. Membership by representatives of these groups, as well as of advocacy groups, is totally appropriate. The lack of a similar requirement that providers serve on these councils is, we

believe, an extremely serious oversight. These providers supply the nexus between the broad program experience of the administrators and the specific treatment experience of the consumers.

Providers of services to the developmentally disabled work with all types of disabilities, in all types of settings, under all types of local, state, Federal, or private programs. Through their work with clients under all of these circumstances, they can identify and speak to the programs' strengths and weaknesses, as well as to the state's planning needs. They can also point out areas of duplication or lack of services for the developmentally disabled which would not be apparent to individual agency administrators or consumers of specific services.

For example, one of our members recently reported that many of her clients need special adaptive equipment. In her locale there are no repair services for many of these devices, and in one case the manufacturer had gone out of business. Knowledge of the existence of this type of problem is not uncommon to providers, but it is not the type of everyday problem or concern that would be apparent to agency administrators or individual consumers.

The Association therefore strongly recommends that when P.L. 94-103 is extended representation of providers be mandated in the composition of the State Planning Councils.

III. SAFE TRANSPORTATION

Current developmental disabilities programs include authorities for transportation services. There appears to be no mention, however, of the need to adapt vehicles to permit comfortable or safe transit for the severely disabled. A bus with standard safety straps, for example, is not sufficient to restrain and transport a child with severe cerebral palsy.

The Association recommends that additional funding be considered to meet the costs of adapting vehicles to provide more appropriate, safe transportation to and from schools, treatment facilities, etc. We also recommend that standards be developed to specify which adaptations actually provide an effective measure of safety for the severely disabled.

IV. INCENTIVE PROGRAMS

In earlier testimony presented to this Subcommittee, the Association made a recommendation for a new legislative incentive. We would like to repeat that recommendation here. We recommend your consideration of legislation that would benefit many handicapped children and also help promote the family unit.

The state of Michigan has adopted a law to encourage middle-income individuals to adopt children with a pre-existing handicap. Under this statute, such a child is automatically eligible for state crippled children's services without regard to the adoptive parent's income.

The Association strongly urges this Subcommittee to consider a Federal incentive program to encourage other states to adopt humanitarian programs of this type. Many families have considered the possibility of adopting a child with a handicap, but have been forced to abandon the prospect because of their fears of the costs of the child's medical, therapeutic, and related needs. All handicapped children, regardless of their categorical designation (developmentally disabled, physically handicapped, emotionally disturbed, learning disabled, etc.) could benefit enormously from a general incentive of this type. More important, they and their adoptive families would be given an opportunity to share their strengths and weaknesses, as well as their hopes and joys. Enactment of a Federal incentive of this type would also help return more handicapped children to stable communities, and assist the public to diminish its misconceptions about handicapped individuals. Our society has often failed to recognize the potential contribution of its handicapped citizens;

enactment of an incentive of this type could be an important step towards the recognition of the human and financial contributions of these people.

V. COORDINATION OF FEDERAL PROGRAMS

There are at least six major public laws which can or do have a direct impact on the care, treatment, or quality of services which are provided for the developmentally disabled. These include:

* P.L. 94-103, the Developmentally Disabled Assistance and Bill of Rights Act
* P.L. 93-516, the Rehabilitation Act, as amended
* P.L. 94-142: the Education for All Handicapped Children Act
* P.L. 94-317, the National Consumer Health Information and Health Promotion Act
* P.L. 94-484, the Health Professions Educational Assistance Act
* P.L. 93-641, the National Health Planning and Resources Development Act.

These are among the many public laws whose provisions provide authorities to meet the needs of the developmentally disabled. We have singled out the six most recent laws to demonstrate the potential that exists for advanced training, research, interdisciplinary training, in-service training, continuing education, consumer information, community screening and evaluation, and overall health planning and coordination.

Specialists in mental retardation facilities, for example, have suggested that special programs of in-service and continuing education be made available to keep up-to-date in client evaluation and treatment and to learn more efficient and effective methods of managing a client's needs. They have also suggested: (1) that there be more programs of

interdisciplinary training; (2) that interdisciplinary teams go out into the community, especially in health service shortage areas, in specialized vans to provide screening and evaluations; and (3) that these same vans be used during weekends to show films and provide other public information on health needs and problems within the community.

It would be easy to suggest that new provisions or incentives be added to P.L. 94-103 to meet these needs. We believe, however, that the authority for these activities already exists in other programs, if only these programs are more closely coordinated.

It is extremely frustrating for the developmentally disabled and for the therapists who are trying to manage their treatment programs to continually encounter red tape and other bureaucratic barriers. We recognize that the enactment of special legislative authorities is designed to emphasize and address the nation's health and treatment needs. Unfortunately, it often obscures or complicates the very programs which are attempting to meet those needs. An individual with physical and developmental disabilities may have to go through dozens of different state, Federal or local programs in order to obtain food, clothing, shelter, treatment, or habilitation. In the case of disabled individuals who do not have parents, guardians, or advocates to assist them in negotiating this maze, the program's benefits may be lost.

I would like to emphasize that we are not advocating program consolidation. We believe that it is appropriate to target programs to meet the nation's needs. However, we believe that the series of separate public laws has, in practice, often resulted in rigid structures which limit program flexibility.

Public Law 93-354 provides an example of the type of coordination we are encouraging. That law extended the diabetes research authority of the National Institute of Arthritis, Metabolism, and Digestive Diseases.

The Congress recognized that the problem of diabetes transcends the rigid, categorical structures of the National Institutes of Health. As a result, the Congress specified that all Federal health programs and activities relating to diabetes be coordinated by the National Institutes of Health, "to provide for the full communication and exchange of information necessary to maintain adequate coordination of such programs and activities." It is this type of coordination, which facilitates communication and program efficiency, that we wish to encourage. We believe greater communication would help to overcome the rigid structures which tend to develop from highly categorized laws or programs.

The Association appreciates this opportunity to share with the Subcommittee our concerns about programs for the nation's disabled citizens. If you have any questions, I will be pleased to respond to them.

3/29/77
met

The American
Occupational Therapy Association, Inc.

April 12, 1977

The Honorable Jennings Randolph
Chairman
Subcommittee on the Handicapped
United States Senate
Washington, D. C. 20510

Dear Mr. Chairman:

Mrs. Susan Hillbrath has requested that I respond to your inquiry of April 1 concerning the Association's affirmative action activities. I have attached her response to your first question, and request that it be included in the hearing record. The answers to your second and third questions are as follows:

"2.) Please provide a listing of any Federal grants your organization has and a description of the activities conducted under such grant."

The Association has no Federal grants at this time.

"3.) What percentage of your employees are handicapped? Please provide a breakdown of the percentage in professional positions and the percentage in clerical positions."

The Association has developed, in cooperation with the seriously handicapped laboratory of Georgetown University and the Center for the Handicapped in Rockville, Maryland, a program to provide a laboratory or employment learning experience for handicapped individuals. The purpose of this program is to provide an opportunity for handicapped individuals to gain training and self-confidence in an actual employment environment, while at the same time providing additional manpower when our work load increases.

Under this program, we currently employ two wheelchair-bound seriously handicapped individuals on a temporary basis. One of these individuals has never before performed in an employment setting; the other, who recently retired from the Civil Service, may become a full-time employee.

All employment opportunities on our staff are first referred to these two centers, and to the Montgomery County job bank for the handicapped. If they are unable to fill these vacancies, we then advertise in the regular employment market. At present, none of our 39 full-time staff

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identify themselves as having a physical handicap.

I hope this information will be helpful to the subcommittee, and shall be pleased to provide any further information.

Sincerely,

James J. Garibaldi
Executive Director

JJG/fm

Attachment

91-852 O - 77 - 11

Additional Information Requested by Senator Randolph
from the American Occupational Therapy Association
PL 94-103

"1.) You state that developmentally disabled persons who are official wards of the State face barriers from the judicial system when there is an opportunity to return to living in the community. How can the advocacy system mandated by the Developmentally Disabled Assistance and Bill of Rights Act impact on this problem?"

The advocacy system mandated by PL 94-103 could impact upon this problem if the state advocacy program (sections 111 and 113 of the Community Mental Health Centers Act) and the state plan provisions (section 133) were modified. This modification should include provisions for liaison with appropriate state and local court systems.

The purpose of this liaison would be twofold: first, to inform judicial and social services personnel about the importance of appropriate placement or treatment of all wards, including the developmentally disabled; and second, to establish mechanisms to expedite the transfer of inappropriately placed wards out of institutions for the developmentally disabled and into the community.

Since official wards often have no family of friends capable of advocating their rights and welfare, we believe there is a special burden upon the state to provide advocates to assist them.

Senator STAFFORD. The Chair will ask Dr. Maurice Kott, if he will, come forward.

Dr. Kott, with apologies to you, this Senator has to leave here for 3 or 4 minutes, but I wonder if you would be willing to go right ahead while Mrs. Forsythe is here, to hear your testimony, and I will be back in 3 or 4 minutes.

STATEMENT OF MAURICE G. KOTT, PH. D., PRESIDENT, NATIONAL ASSOCIATION OF COORDINATORS OF STATE PROGRAMS FOR THE MENTALLY RETARDED, INC., DIRECTOR OF THE DIVISION OF MENTAL RETARDATION, TRENTON, N.J.; ACCOMPANIED BY ROBERT GETTINGS, EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF COORDINATORS OF STATE PROGRAMS FOR THE MENTALLY RETARDED

Dr. KOTT. Certainly, sir.

Mrs. Forsythe, we have a statement, more complete testimony than I will be prepared to ad lib at this time.

In the interest of the committee's time, I will file it with the committee and restrict my oral remarks to a few things that I wish to highlight.

May I invite your attention to the fact that I have with me Mr. Robert Gettings, who is the executive director of the National Association of Coordinators of State Programs for the Mentally Retarded.

I am the director of the Division of Mental Retardation in the State of New Jersey, and serve as president of the National Coordinators of State Programs for the Mentally Retarded.

We appreciate the opportunity to appear before this committee to present our views on the operation of Federal assistance programs affecting handicapped citizens.

The membership of our association consists of the designated officials in the 50 States and territories who are directly responsible for the provision of residential and community services to a total of over ½ million mentally retarded children and adults.

As a result, we have a vital stake in a variety of Federal health, education and social welfare programs.

I plan to focus on two key pieces of expiring Federal legislation.

The first of these is Developmental Disabilities Act and the second is aid to handicapped children under title I of the Elementary and Secondary Education Act.

Largely as a result of the forthright leadership of this subcommittee and its counterpart units in the House, a broad array of Federal health, education, rehabilitation and social service benefits have been made accessible to severely handicapped Americans over the past decade.

However, because of the lack of effective interagency coordination, inadequate resources and the permissive nature of some programs, the actual extent, range and quality of services to such clients has improved very little.

This leads to the dangers expressed in American folklore that everybody's business is nobody's business.

The Federal Government currently lacks a clear set of overarching principles to guide its efforts on behalf of developmentally disabled and other severely handicapped persons.

This policy vacuum is particularly evident in the Federal response to efforts to deinstitutionalize programs for the mentally retarded.

This is a critical area for the organization and the members that I represent and we would be glad to elaborate when the committee is prepared to deal with this issue.

Our problem is that the responsibility for the current lack of a coherent, government-wide deinstitutionalization policy cannot simply be laid at the footsteps of the specific Federal agencies involved. For the most part, these agencies are diligently pursuing the statutory mandates set out for them by Congress.

In the case of most generic service agencies, however, this mandate contains no reference to deinstitutionalization or any of the other programmatic philosophies current in the field.

In part, then, the underlying problem can be traced in the manner in which Congress is organized to consider new Federal initiatives and as a consequence the manner in which the Federal Government is organized to consider new initiatives.

In this regard, we might point out that we believe this subcommittee, the only unit in Congress with an exclusive mandate to consider Federal laws affecting the handicapped, has legislative jurisdiction over less than 15 percent of the Federal dollars which will be obligated on behalf of mentally retarded citizens in the current fiscal year. Given the barriers to the development and implementation of a coordinated set of interagency policy goals on behalf of the developmentally disabled, the formulation of legislative and administrative solutions will not be an easy task.

When the developmental disabilities program was initially authorized by Congress in 1970, the legislation was seen as a planning, coordinating and gap-filling mechanism which would assist consumer representatives, service providers and responsible State officials to make rational sense of the growing array of Federal and State programs to finance and deliver services to a target population of some of the most severely handicapped persons in our society.

In looking back over the past 6 years, however, it seems clear that the developmental disabilities program has not achieved the high expectations which many consumer advocates and professionals held in 1970. At the same time, the fundamental objectives which the original legislation addressed are, if anything, even more meaningful today than they were 6 years ago.

We feel the following are the major operational problems which Congress must address.

First, there is confusion surrounding the planning and service roles of the council. In passing the 1975 amendments to the act, Congress intended to place greater emphasis on the council's role as a focal point for comprehensive Statewide planning on behalf of the developmentally disabled.

However, as any planner will tell you, to be effective, the planning and implementation functions must be part of the same cyclical process.

When the two functions are divorced from one another, we usually end up with useless plans and unplanned programs.

In the past, furthermore, the planning process has so often been used as a stalling or diversionary tactic that many consumer, pro-

vider and agency representatives on State councils are resistant to spending too much time on developing plans.

They say, "we know what has to be done without drawing up a lot of fancy plans that will never be read. Let us get on with the task of implementation."

Finally, some reasonable differentiation must be made between the council's global, Statewide, planning role and the operational planning functions of the various State and local agencies engaged in serving the developmentally disabled.

As an example, this fiscal year, the State which I represent will spend approximately $84 million on daytime and residential services to mentally retarded citizens in the State of New Jersey. To properly execute the duties assigned to the division of mental retardation by State law, it is absolutely essential that the division's staff engage in planning activities at various levels within the service system.

The way in which operational planning efforts should intersect with the broad, interagency planning responsibilities of the developmental disabilities council is an issue which needs to be addressed and clarified.

Second, the lack of a clear set of national service/planning objectives around which the program can coalesce. One of the basic difficulties associated with the program from its onset has been the diffuse set of goals. The gap-filling philosophy underlying the legislation has proven to be too nebulous a target for many State councils.

Third, the limited impact of council activities on the wide range of Federal-State programs serving developmentally disabled persons. One of the basic tenets of the Developmental Disabilities Act is that, because of the scope and longevity of the target population's needs, maximum progress can be achieved through an interagency effort to access and coordinate the activities of a variety of health, education, rehabilitation and social services agencies which have a role to play in serving the developmentally disabled.

While convincing arguments for this approach have been advanced over the years, in most States the program has had little or no influence on the policies and practices of the Federal-State service programs which are available in the State.

The broad nature of the council's planning mandate, the absence of specific legal provisions for enforcing interagency cooperation, the lack of a planning orientation among most consumer and provider members of councils and inadequate data upon which to base sound planning strategies are all contributing factors.

Fourth, there is the lack of a clear differentiation between the functional responsibilities of the State planning council and those of the designated State administering agencies.

The original 1970 legislation made it clear that the council was to play more than simply an advisory role in the formulation of Federal-State spending priorities.

The 1975 amendments to the act attempt to distinguish between council and agency roles. These attempts are improvements, but there is still confusion in the States and, as a matter of fact, today members of my staff are meeting with New Jersey's Developmental Disabilities Council staff to decide which aspect of the responsibility belongs to Caesar and which belong, in effect, to the developmental disabilities council.

It is clear that the clarifying legislation has been helpful but has not gone far enough. We feel that the basic problem is the failure to distinguish between legal, fiscal, and programmatic responsibility for the program.

These problems are formidable, but not insoluable within the context of the existing program.

Congress could establish, by statute, a limited number of nationally identified service objectives for the program, which require the involvement of two or more major service delivery agencies, and then draw a clearer statutory division between the planning role of the council and the service delivery role of the designated State agency in carrying out these objectives.

In addition to identifying the target program areas, the statute could mandate that certain designated administering agencies under other Federal-State grant programs participate in a particular activity.

For example, if rehabilitation of developmentally disabled were to be designated as a target program area, it would be logical for Congress to mandate the participation of the State rehabilitation and MR/DD agencies in the process of developing and implementing plans to increase the access of DD persons to rehabilitation services.

Then, based upon a statutory mandate, the State council would be responsible for submitting an initial plan for developing an interagency approach to improving services to developmentally disabled persons through the particular target program.

Incorporated in this plan would be the designation of those agencies which would participate in this planning effort, including the designation of the lead agency.

Among the advantages of this approach is that the activities of the program would be targeted on the achievement of specific goals in high priority service need areas.

As a result, progress would be quantifiable, thus providing Congress, the executive branch, and State officials with specific yardsticks for evaluating the successes and failures of the program.

In addition, by focusing on a limited set of programmatic objectives and assigning different functional responsibilities to the council and service agencies, it should be possible to reduce the degree of friction in council-agency relationships as well as get more accomplished with the Federal funds available under the Developmental Disabilities Act and related Federal programs.

I would like to touch just for a moment on the aid to State supported education programs for handicapped persons.

According to the Bureau of Education for the Handicapped statistics, approximately 60 percent of title I, ESEA funds expended on handicapped children in State operated and supported programs, are being used to educate mentally retarded children. It is our estimate that approximately $66 million annually is being expended on title I aid on behalf of the mentally retarded.

Within most States these funds are administered by the State mental retardation agency. At the request of the staff of the House Education and Labor Committee our association recently completed a survey of State mental retardation directors concerning the utilization of title I funds and possible steps Congress might take to pre-

vent overlap with the Education for All Handicapped Children's Act the program.

The findings and conclusions of this survey, which are now being of 1975, and otherwise improve the existing statutory authority for compiled, will be shared with the subcommittee's staff within the near future.

In the meantime, I would like to discuss several of the general conclusions which can be drawn from a preliminary analysis of the responses received to date.

First, handicapped children in State operated and supported schools have derived tremendous benefits from the title I ESEA program since it was initially authorized by Congress in 1965. In many cases, the severely retarded and multiply handicapped youngsters who are benefiting from the program were previously denied access to any education and training services.

Second, continuation of a separate, identifiable program of Federal assistance on behalf of children in State supported facilities is absolutely essential, at least for the foreseeable future. Despite the passage of Public Law 94-142, with its strong emphasis on a zero reject educational system, the quality and scope of programs for children in most State operated and supported facilities would suffer if title I benefits were folded into part B of the Education of the Handicapped Act at this point in history.

Third, there is a need to improve the legislative and administrative interface between part B and title I programs.

Fourth, the deinstitutionalization incentive, built into the 1974 amendments to title I, needs to be either eliminated or sharply modified. It is our experience that it has been of little or no consequence.

In conclusion, we certainly appreciate this opportunity to share the association's views with the subcommittee.

We recognize that your past efforts to eliminate barriers to the full participation of mentally retarded citizens in our society are deeply appreciated by the association's members and by the citizens of this country.

For our part, we pledge our full support and cooperation as you consider the important legislation before you this year.

Thank you.

Senator STAFFORD. Thank you very much, Dr. Kott.

Without objection, the Chair intends to place your entire statement in the record so that all members of the subcommittee will have an opportunity to read it.

Dr. KOTT. We appreciate it, Senator.

Senator STAFFORD. And we have one question for you which we would like to submit to you in writing for response in writing, and again, in view of our constraints of time this morning——

Dr. KOTT. We will be glad to respond, Senator.

Senator STAFFORD. We are very grateful to you and your associate for coming here, for the kind words about this subcommittee, and your assistance in our coming deliberations.

Dr. KOTT. Thank you very much.

[The prepared statement of Dr. Kott and information referred to follows:]

STATEMENT OF TESTIMONY

AT

OVERSIGHT HEARINGS ON

FEDERAL PROGRAMS FOR THE HANDICAPPED

Respectfully Submitted

to the

SUBCOMMITTEE ON HANDICAPPED
COMMITTEE ON HUMAN RESOURCES
U. S. SENATE

The Honorable Jennings Randolph, Chairman

Maurice G. Kott, Ph.D., President

National Association of Coordinators of State
Programs for the Mentally Retarded, Inc.

and

Director, Division of Mental Retardation
New Jersey Department of Human Services

March 31, 1977

Mr. Chairman, and distinguished members of the Subcommittee, I appreciate this opportunity to appear before you to present the views of the National Association of Coordinators of State Programs for the Mentally Retarded on the operation of federal assistance programs affecting handicapped citizens.

The membership of our Association consists of the designated officials in the fifty states and territories who are directly responsible for the provision of residential and community services to a total of over 1/2 million mentally retarded children and adults. As a result, we have a vital stake in a variety of federal health, education and social welfare programs. In recent years, as states have begun to emphasize the development of a wide range of residential and daytime alternatives to large, publicly-operated institutions, the number, scope and complexity of federal assistance programs impacting on state mental retardation agencies has increased tremendously.

This morning I would like to outline for the Subcommittee some of the critical problems facing state mental retardation officials in attempting to appropriately utilize the various forms of federal assistance available. In addition to describing the general issues involved, I plan to focus attention on two key pieces of expiring federal legislation - the Developmental Disabilities Act and aid to handicapped children under Title I of the Elementary and Secondary Education Act. During the current session of Congress, this Subcommittee will be considering legislation to extend and amend the statutory mandates for these two programs and, therefore, it seems both timely and appropriate to describe our experience as state officials who have been intimately involved in the day-to-day operation of these programs. At a later date, when the Subcommittee schedules legislative hearings on these two programs, the Association will be prepared to discuss, in greater detail, possible legislative remedies to identified weaknesses in these programs.

A. The Federal Policy Vacuum

Largely as a result of the forthright leadership of this Subcommittee and its counterpart units in the House, a broad array of federal health, education, rehabilitation and social service benefits have been made accessible to severely handicapped Americans over the past decade. However, because of the lack of effective interagency coordination, inadequate resources and the permissive nature of some programs, the actual extent, range and quality of services to such clients has improved very little. "Everyone's problem" becomes no one's responsibility and the local program manager is left with the impossible task of orchestrating available generic and specialized health, education and social welfare programs which often have inconsistent and conflicting operational goals and policies. The ultimate victim is the severely handicapped individual who, once again, fails to receive the varied continuum of training and support services he or she requires over a prolonged period of time.

The federal government currently lacks a clear set of overarching principles to guide its efforts on behalf of developmentally disabled and other severely handicapped persons. This policy vacuum is particularly evident in the federal response to efforts to "deinstitutionalize" programs for the mentally retarded.

Each federal agency with an actual or potential impact on deinstitutionalization

of the mentally retarded tends to develop its operational policies with limited regard to their impact on ancillary programs operated by other federal and state agencies and with little or no sensitivity to the overall impact of the federal government's efforts at the state and local level. This point was made quite graphically in a recent report by the General Accounting Office on deinstitutionalization of the mentally disabled. The report concluded:

> A basic problem at the Federal, State, and local levels is that those agencies primarily responsible for the mentally disabled do not have the funds needed to develop adequate . . . care systems . . . (nor) the responsibility for . . . the standards of care in communities. Therefore, they have approached deinstitutionalization by relying on the many social, welfare, and other programs that affect such target groups as the poor, the aged, children, or the disabled, to accomplish deinstitutionalization individually without any central guidance or management.
>
> [We found that,] in the absence of a national strategy or management system to implement deinstitutionalization, Federal officials responsible for other programs that affect deinstitutionalization generally (1) were not aware of the national goal or had not received instructions on implementation, (2) had not implemented their programs to help achieve the goal, (3) had not undertaken joint efforts directed at deinstitutionalization, or (4) had not monitored or evaluated their programs' impact on deinstitutionalization.[1]

Yet, as anyone who has ever worked in a large bureaucratic organization knows, the impediments to effective interagency coorperation are, to say the least, formidable - especially if there is no clear statutory or executive mandate to undergird the effort. Despite the best intentions of everyone involved, past experience indicated that such efforts usually flounder for a variety of reasons.

The responsibility for the current lack of a coherent, government-wide deinstitutionalization policy, however, cannot simply be laid at the footsteps of the specific federal agencies involved. For the most part, these agencies are diligently pursuing the statutory mandates set out for them by Congress. In the case of most generic service agencies, however, this mandate contains no reference to deinstitutionalization or any of the other programmatic philosophies current in the field. Indeed, even though millions of dollars may be expended on our target population, services to the developmentally disabled aren't even an identified program objective of these agencies.

In part, then, the underlying problem can be traced to the manner in which Congress is organized to consider new federal initiatives. We might point out, for example, that this Subcommittee - the only unit in Congress with an exclusive mandate to consider federal laws affecting the handicapped - has legislative jurisdiction over less than fifteen percent of the federal dollars which

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[1] General Accounting Office, Returning the Mentally Disabled to the Community: Government Needs to Do More, (Rept. No. HRD-76-152), January, 1977.

will be obligated on behalf of mentally retarded citizens in the current fiscal year.[2]

An effective, interagency approach to deinstitutionalization would require cooperation among at least four or five major committees in both the House and Senate. However, if we accept normalization of services and service support mechanisms as a guiding principle, it is both totally unrealistic and undesirable to expect Congress, as a whole, to organize itself around the interests of the severely handicapped or, as far as that goes, any other categorical interest group.

Given these endemic barriers to the development and implementation of a coordinated set of interagency policy goals on behalf of the developmentally disabled, the formulation of legislative and administrative solutions will not be an easy task. While we don't come to you today with any simple, pre-package solutions to the problems identified above, we do feel that serious consideration of the issues involved is long overdue.

B. The Developmental Disabilities Program

When the Developmental Disabilities Program was initially authorized by Congress in 1970, the legislation was seen as a planning, coordinating and gap-filling mechanism which would assist consumer representatives, service providers and responsible state officials to make rational sense of the growing array of federal and state programs to finance and deliver services to a target population of some of the most severely handicapped persons in our society. In looking back over the past six years, it seems clear that the DD program has not achieved the high expectations which many consumer advocates and professionals held in 1970. At the same time, the fundamental objectives which the original legislation addressed are, if anything, even more meaningful today than they were six years ago. Therefore, in our opinion, the question Congress should be asking is: how can the goals of the program be accomplished in a more effective and efficient manner?

We are certain that this Subcommittee will receive a wide range of views on the barriers to accomplishment of DD program goals. Clearly, there are a variety of issues to consider. For purposes of today's testimony, however, I plan to focus only on what seems to us to be the most fundamental and farreaching issues. Should members of the Subcommittee have other questions concerning the operation of the program, we would be happy to respond, either during the question and answer period or in subsequent legislative hearings on the Act.

The following are the major operational problems which we feel Congress must address:

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[2] Based on a report entitled "Obligations for Mental Retardation Activities: FY 1975-77", prepared for the House Appropriations Subcommittee on Labor-HEW by the Office for Handicapped Individuals, HEW.

1. Confusion surrounding the planning and service roles of the council. In passing the 1975 amendments to the Act, Congress intended to place greater emphasis on the council's role as a focal point for comprehensive statewide planning on behalf of the developmentally disabled. This fact is reflected in the revised name of the council and the increased emphasis on this aspect of the council's role.

   However, as any planner will tell you, to be effective, the planning and implementation functions must be part of the same cyclical process. When the two functions are divorced from one another, we usually end up with useless plans and unplanned programs.

   Besides, in the past, the planning process has so often been used as a stalling or diversionary tactic that many consumer, provider and agency representatives on state councils are resistant to spending too much time on developing plans. Their attitude is: "we know what has to be done without drawing up alot of fancy plans that will never be read. Let's get on with the task of implementation."

   Finally, some reasonable differenciation must be made between the council's global, statewide planning role and the operational planning functions of the various state and local agencies engaged in serving the developmentally disabled. For example, this fiscal year the state agency I direct will expend approximately $84 million on daytime and residential services to mentally retarded persons in New Jersey. To properly execute the duties assigned to the Division of Mental Retardation by state law, it is absolutely essential that the Division's staff engage in planning activities at various levels within the service system. The way in which such operational planning efforts should intersect with the broad, interagency planning responsibilities of the DD council is an issue which needs to be addressed.

2. Lack of a clear set of national service/planning objectives around which the program can coalesce. One of the basic difficulties associated with the program from its on-set has been the diffuse set of goals. The gap-filling philosophy underlying the legislation has proven to be too nebulous a target for many state councils. In addition, the lack of clear objectives has made it difficult to evaluate the impact of the program both within the state and nationally.

3. Limited impact of council activities on the wide-range of federal/state programs serving developmentally disabled persons. One of the basic tenets of the Developmental Disabilities Act is that, because of the scope and longevity of the target population's needs, maximum progress can be achieved through an inter-agency effort to access and coordinate the activities of a variety of health, education, rehabilitiation and social services agencies which have a role to play in serving the developmentally disabled. While convincing arguments for this approach have been advanced over the years, in most states the program has had little or no influence on the policies and practices of the federal/state service programs mentioned in Section 134(b)(2) of the Act.

   The reasons why councils in many states have failed to serve as an

effective mechanism for interagency coordination are difficult to assess. However, the broad nature of the council's planning mandate, the absence of specific legal provisions for enforcing interagency cooperation, the lack of a planning orientation among most consumer and provider members of councils and inadequate data upon which to base sound planning strategies are all contributing factors. The high turnover rate among agency, consumer and provider representatives on councils[3] has also made it difficult to maintain a continuity of purpose and function, especially in view of the unique statutory goals of the program.

4. The lack of a clear differenciation between the functional responsibilities of the state planning council and those of the designated state administering agency. The original 1970 legislation (P.L. 91-517) made it clear that the council was to play more than simply an advisory role in the formulation of federal/state spending priorities. Yet, the precise dimensions of the council's responsiblities were not made clear in the legislation. Since the implementing regulations failed to deal with this matter, each state was largely left to its own devices to determine the working relationship between its council and designated state agency. As a result, the various states evolved quite different patterns of agency/council interaction - varying from states in which the council was almost totally independent of the administering state agency to states where the council served as simply an advisory body to the state agency.

   The 1975 amendments to the Act (P.L. 94-103) attempt to distinguish between council and agency roles. In essense, the revised Act assigns responsibilities for day-to-day administration of the program, including the awarding of grant funds, to the state agency and focuses the council's activities on system-wide advocacy, comprehensive planning, supervising the development of the state plan and evaluating the state's overall efforts on behalf of the developmentally disabled. One of the key elements in this reallignment of council/agency responsibilities is the requirement that the agency prepare a "design for implementation" - i.e., a detailed plan, consonent with council identified needs and spending priorities, for using the state's annual allotment under the DDSA program.

   However, despite this clarifying legislative language and the recent issuance of final implementing regulations, it seems certain that further questions will arise concerning such issues as the preparation of the state plan, supervisory responsibility for council staff and control over the disbursement of DDSA grant funds which will interfere with the smooth functioning of the program.

5. Failure to distinguish between legal, fiscal and programmatic responsibility for the program. The original legislation reflected a concern

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[3] Stedman, Donald J., and Linda D. Baucom, "A Comparison of State Developmental Disabilities Council Member Characteristics as a Function of Member Status (Consumer/Non-Consumer) and Size of Federal DD Formula Grant," Frank Grahan Porter Child Development Center, The University of North Carolina at Chapel Hill, 1975 (mimeo).

that consumer representatives not be shut out of effective and meaningful participation in the decision-making process. At the same time, legal and fiscal accountability for the operation of the DDSA program was fixed with state government, as represented by the designated state administering agency. While this delicate balance between consumer participation and state agency accountability has been achieved in some jurisdictions, in others it clearly has not.

At the one extreme, consumer representatives on some councils have tended to equate consumer involvement with total control over the allocation of DDSA formula grant funds. Such consumers generally perceive the limited federal funds available to be "our money" and actively resist any state agency encroachment on their perogatives to distribute DDSA grants. One of the unfortunate side effects of this attitude is that such councils usually have little or no impact on the policies and practicies of the major federal/state programs affecting developmentally disabled children and adults within the state. In other words, they fail to fulfill the central operating goal of the legislation.

At the other extreme are those jurisdiction where the state agency has played the dominant role and the council has been relegated to a secondary position, with little real involvement in decision-making. In such situations, the program becomes simply an extension of the activities of the designated state agency and, again, the program has little or no impact as a mechanism for interagency coordination and comprehensive planning.

The above problems are formidable but not insoluable within the context of the existing program. The following is one approach which might be taken to remedy the problems we have identified.

Congress could establish, by statute, a limited number of nationally identified service objectives for the program, which require the involvement of two or more major service delivery agencies, and then draw a clearer statutory division between the planning role of the council and the service delivery role of the designated state agency(ies) in carrying out these objectives. Under such a plan, two or three target program areas would be selected by Congress for special emphasis within each state's overall DDSA plan. Examples of possible target program areas which might be selected for special emphasis include: (a) vocational rehabilitation of developmentally disabled adolescents and adults; (b) community residential services; (c) education of multi-handicapped developmentally disabled children in residential settings; and (d) early case finding and screening of developmentally disabled infants.

In addition to identifying the target program areas, the statute could mandate that certain designated administering agencies under other federal/state grant programs participate in a particular activity. For example, if rehabilitation of developmentally disabled were to be designated as a target program area, it would be logical for Congress to mandate the participation of the state rehabilitation and MR/DD agencies in the process of developing and implementing plans to increase the access of DD persons to rehabilitation services.

A general timetable for dealing with each of the identified target areas might also be set out in the statute. Included would be both an initial planning phase and an implementation phase for each area. In order to facilitate orderly planning and spread out the fiscal impact, the initial target areas might be phased in over a three year period.

Based on such a statutory mandate, the state council would be responsible for submitting an initial plan for developing an interagency approach to improving services to developmentally disabled persons through the particular target program. Incorporated in this plan would be the designation of those agencies which would participate in this planning effort, including a lead agency.

Once the completed interagency plan was prepared, reviewed and approved, the state would qualify for two years of grant support to assist in implementing activities in each nationally selected target program area. The appropriate state service agency (usually the lead planning agency) would be designated to administer these funds; however, the overall action plan might call for two or more agencies to carry out grant-funded service activities.

After receiving feedback on the results of the implementation phase in the various states, Congress then could determine whether some measure of continued federal support was justified. If so, the activity could either be picked up as part of a general expansion in federal support for the particular program or as a separate authority under the appropriate piece of federal legislation (e.g., Education of the Handicapped Act, Maternal and Child Health and Crippled Children's Act, Rehabilitation Act, etc.).

Under this proposed schema the council would be responsible for overall, state-wide planning and for the coordination and monitoring of the various targeted service activities authorized under the Act. State service agencies, on the other hand, would be charged with participating in the detailed planning and service delivery activities which relate to their specific areas of expertise and responsibility under federal and state law.

Among the advantages of this approach is that the activities of the program would be targeted on the achievement of specific goals in high priority service need areas. As a result progress would be quantifiable, thus providing Congress, the Executive Branch and state officials with specific yardsticks for evaluating the successes and failures of the program. In addition, by focusing on a limited set of programmatic objectives and assigning different functional responsibilities to the council and service agencies, it should be possible to reduce the degree of friction in council-agency relationships as well as get more accomplished with the federal funds available under the Developmental Disabilities Act and related federal programs.

C. Aid to State Supported Education Programs for Handicapped Children

According to the Bureau of Education for the Handicapped statistics, approximately 60 percent of Title I, ESEA funds expended on handicapped children in state operated and supported programs (or roughly $66 million) are being used to

educate mentally retarded children. Within the states, these funds are administered by state mental retardation agencies. Therefore, as an Association, we have a major interest in the Title I grant program for handicapped youngsters.

At the request of the staff of the House Education and Labor Committee, NACSPMR recently completed a survey of state mental retardation directors concerning the utilization of Title I funds and possible steps Congress might take to prevent overlap with the "Education for All Handicapped Children's Act of 1975" (P.L. 94-142) and otherwise improve the existing statutory authority for the program. The findings and conclusions of this survey, which are now being compiled, will be shared with the Subcommittee's staff within the near future. In the meantime, the following general conclusions can be drawn from a preliminary analysis of the responses received to date:

- Handicapped children in state operated and supported schools have derived tremendous benefits from the Title I ESEA program since it was initially authorized by Congress in 1965. In many cases the severely retarded and multiply handicapped youngsters who are benefiting from the program were previously denied access to any education and training services. Instead, they were left to wile away their lives at home or in the back wards of large, sterile state institutions. In many state-run facilities, Title I aid has been the single most important impetus to the initiation and expansion of educational programs for severely handicapped youngsters.

- Continuation of a separate, identifiable program of federal assistance on behalf of children in state supported facilities is absolutely essential - at least for the foreseeable future. Despite the passage of P.L. 94-142, with its strong emphasis on a zero reject educational system, the quality and scope of programs for children in most state operated and supported facilities would suffer if Title I benefits were folded into Part B of the Education of the Handicapped Act at this point in history. This conclusion is clearly documented in responses to NACSPMR's recent survey. Among the most frequently cited reasons for anticipating a decline in federal support were: (a) the likelihood that SEA's and LEA's, under a consolidated program, would sharply reduce the current level of federal aid flowing to state supported schools - especially in view of the wide discrepancy in per capita aid levels under the Title I and Part B programs; (b) serious doubts that Congress would be willing to approve the same level of funding for a consolidated program as it would for separate programs - particularly considering the sharp increases contemplated in Part B funding; and (c) the fact that, in a majority of states, legal responsibility for providing educational services to children in state schools still rest with an agency or agencies other than the education department.

- There is a need to improve the legislative and administrative interface between Part B and Title I programs. Among the specific issues refered to by the respondents to the recent NACSPMR survey are: (a) differentiating between the Title I and Part B counts of eligible children; (b) identifying the circumstances under which parents can be held financially liable for the non-educational costs (i.e., room, board and medical and related care) of Title I eligible youngsters; (c) fixing responsibility

for case management and service delivery for multi-handicapped youngsters residing in Medicaid-eligible long term care facilities (where both an individualized education plan and an individualized habilitation plan must be prepared on the child).

- The "deinstitutionalization" incentive, built into the 1974 amendments to Title I, needs to be either eliminated or sharply modified. Many of the respondents to our recent survey indicated that the 1974 provision has had little or no impact on the placement activities of public institutions. Indeed, because of the Title I hold harmless language adopted by Congress that same year, the deinstitutionalization incentive has resulted in resources being drained away from state-run facilities to reimburse local school districts. Obviously, this process of "robbing Peter to pay Paul" does little to accomplish our overall goal of assuring that all handicapped children receive the appropriate educational services they need at the earliest possible date.

When the Subcommittee schedules hearings on Title I programs, the Association will be pleased to elaborate on these problems and suggest possible legislative remedies. In the meantime, we trust that the above information will prove helpful.

* * * * * * * * * * *

We appreciate this opportunity to share the Association's views with the Subcommittee. Your past efforts to eliminate barriers to the full participation of mentally retarded citizens in our society are deeply appreciated by the Association's members. For our part, we pledge our full support and cooperation as you consider the important legislation before you this year.

91-852 O - 77 - 12

National Association of Coordinators
of State Programs for the Mentally Retarded, Inc.
2001 Jefferson Davis Highway · Arlington, Virginia 22202 · 703/920-0700

Robert M. Gettings, Executive Director

MAY 23 1977

May 19, 1977

The Honorable Jennings Randolph
Chairman
Subcommittee on the Handicapped
Committee on Human Resources
United States Senate
Washington, DC 20510

Received

Dear Senator Randolph:

NACSPMR President, Dr. Maurice Kott, has asked me to respond to the questions raised by the Subcommittee in your letter dated April 1.

Our answers are contained in Enclosure A.

I apologize for our delay in responding but we encountered some difficulty in gathering information to respond to your second question.

Should you require additional information or if we can be of further assistance to the Subcommittee, please feel free to call upon us.

Sincerely,

Robert M. Gettings
Executive Director

RMG:ra
Encl.
cc: Dr. Maurice Kott

Enclosure A

Answers to Questions Raised
by the
Senate Subcommittee on the Handicapped

1. Do you have recommendations on how operational planning efforts can be coordinated with the interagency planning responsibilities of the State developmental disabilities councils?

As NACSPMR President Maurice G. Kott stressed in his March 31 testimony before the Subcommittee, the Association believes that Congress should clarify the role of state councils and state agencies by: (a) assigning the responsibility for global, interagency planning, coordination and monitoring to the council; and (b) establishing a limited number of nationally identified service objectives which require the involvement of two or more major state agencies. Once Congress specified the area or areas in which it wished the states to concentrate their service efforts, the council's role would include: (a) the identification of the appropriate state service agencies to participate in the development of an operational plan for improving programs and activities in the specified service area; and (b) monitoring the performance of these agencies. On the other hand, the state agencies designated to participate in the operational planning and implementation phase would be charged with developing and carrying out the service delivery plan.

One of the major advantages of this approach is that the state council and the legally responsible state service agencies would be assigned, by law, differential planning roles appropriate to their overall missions. The council would be able to concentrate a greater portion of its efforts on the development of the overall statewide plan, and, through systematic advocacy and interagency coordination, promote the elimination of barriers to fuller participation by the developmentally disabled in the opportunities of society. When it comes to laying plans for the commitment of DD service dollars, however, the responsibility would rest with a consortium of two or more state agencies designated to stimulate improvements in the particular target service area (with one agency selected as the lead agency for planning and implementation).

If this approach were adopted, the involved state agencies could be required to demonstrate how the limited federal DD dollars would be used in conjunction with local, state and federal funds available from other sources to stimulate improvements in the scope, range and quality of services provided in the statutorily designated target area. In addition, by targeting DD service funds on a limited number of Congressionally selected areas it should be possible to evaluate the nationwide, regional and intrastate impact of the program, a task which is most difficult at present because of the diverse goals of the program.

2. Can you provide documentation regarding your statement that the deinstitutionalization incentive has resulted in resources being drained away from State-run facilities to reimburse local school districts?

When Dr. Kott testified before the Subcommittee in late March, he indicated that the Association was in the process of conducting a survey of problems surrounding the utilization of federal aid to state operated and supported schools for handicapped children (authorized under Title I, ESEA, as amended by P.L. 89-313). As

promised in Dr. Kott's testimony, a copy of the final survey report has been shared with the Subcommittee's staff.

The report concludes, in part, that "some state officials . . . alluded to the funding trade-off which occurs when 313 monies are transferred to LEA's - i.e., reduced services to children in 313 programs - and questioned the social utility of such a policy in view of the federal/state/local funding base currently available to handicapped children served in local public schools" (see pp. 7-10 of Enclosure B for additional information).

The Association's staff has also reviewed statistical reports on the program made available by the Bureau of Education for the Handicapped. The summary report on 89-313 expenditures during FY 1977 shows that a total of 75 out of 143 state agencies participating in the 313 program during the current fiscal year - or slightly over one-half - are still operating at a hold-harmless level. It follows logically that any of these hold-harmless agencies which deinstitutionalizes a child and transfers part of its allotment to the responsible LEA has less funds to educate the children who remain in the facility. Of course, if the placement of the child causes a net reduction in the state run facility's population, per capita education funds will remain unchanged. However, in the typical facility the former resident is quickly replaced by another youngster who requires institutionalization. The problem is that an agency operating at the hold harmless level qualifies for no additional 313 funds as a result of such a new admission.

Unfortunately, the reporting format of the BEH statistics makes it impossible to determine the fiscal and demographic impact of this trade off situation. But given the relatively low number of deinstitutionalized children reported in FY 1977 (15,963 out of a total of 201,429 children counted), it seems reasonable to hypothesize that the fiscal disincentive to transferring funds acted as a significant detterant to reporting children placed back into LEA's. At least, this is an avenue of investigation which the Association feels deserves further exploration by the Subcommittee.

3. Please provide a list of the Federal grants your organization has and a description of the activites conducted under each grant.

At the present time, the Association is conducting one grant-funded activity. Information concerning this grant is summarized in the attached fact sheet (see Enclosure C).

Since the grant project was launched late last year, the staff, with the assistance of the Project Advisory Board, had selected the following three broad generic service areas in which to concentrate its efforts: income maintenance, housing and health. Work is currently proceeding on a series of indepth issue papers and the identification of specific strategies for eliminating barriers to fuller participation by the developmentally disabled in such programs as Supplementary Security Income, Social Security, etc.

If the Subcommittee is interested, we would be glad to share with you additional information about the project as well as copies of materials prepared by the project staff.

4. What percentage of your organization's employees are handicapped? Please provide a breakdown of the percentages of professional positions and the percentage in clerical positions.

At the present time, NACSPMR employs a total of nine persons (6 professional; 3 secretarial/clerical), none of whom are physically or mentally handicapped. However, practically since the inception of the Association's offices, over six years ago, NACSPMR has used the services of the Sheltered Occupational Center in Arlington, Virginia to print, collate and mail all Association newsletters and publications. As the organization's activities in this area have grown, so has the amount of business we have channelled to SOC. For example, last fiscal year NACSPMR paid SOC a total of $12,690, or slightly over 11 percent of the Association's total operating budget.

We are aware that contract work is no substitute for having a handicapped person on the staff. Unfortunately, our past efforts to recruit a qualified handicapped individual for the small number of staff positions available have been unsuccessful. The major problem seems to be the limited pool of qualified physically handicapped individuals working in the field of mental retardation. In addition, as a small office (4.5 permanent positions and 4.5 temporary, grant-funded slots), the Association cannot justify the establishment of highly specialized positions where mentally retarded workers might be employed.

Despite these impediments we intend to continue our efforts to recruit an appropriate and qualified handicapped person for the Association's staff as position vacancies become available.

APPENDIX B

SURVEY REPORT

on

FEDERAL AID TO STATE OPERATED AND
SUPPORTED SCHOOLS FOR THE HANDICAPPED

April 25, 1977

Prepared by
National Association of Coordinators
of State Programs for the Mentally Retarded, Inc.

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SURVEY REPORT
on
Federal Aid to State Operated and
Supported Schools for the Handicapped

I. Background

In 1965 Congress amended Title I of the Elementary and Secondary Education Act to authorize federal financial assistance on behalf of children in state operated and state supported schools for handicapped children (P.L. 89-313). This amendment to Title I was enacted only months after the landmark Elementary and Secondary Education Act, which provided the first broad-based authority for federal aid to local public schools, was signed into law by President Johnson. The rationale underlying P.L. 89-313 was that children in state institutions and other publicly financed education programs outside the local public schools should be entitled to federal assistance paralleling general Title I aid. In addition, it was argued that the federal government has a special obligation to help institutionalized children who often are among the most educationally deprived youngsters in our Nation.

Early this year the minority staff of the House Education and Labor Committee developed a questionnaire concerning the operation of the 89-313 program (see Attachment A). Since the statutory authority for the program expires next year the Committee must decide whether to extend or amend the legislation during 1977. Through the questionnaire the staff hoped to elicit information which would be helpful to the Committee in reaching such a decision.

The questionnaire attempted to elicit the views of state officials concerning: (a) whether the 89-313 program should be continued, especially in light of the emphasis on serving all handicapped youngsters in the "Education for All Handicapped Children Act of 1975"(P.L. 94-142); and (b) if so, what modifications need to be made in the program to make it consonant with P.L. 94-142 and to eliminate any other operational problems.

The Committee mailed the questionnaire to all state and territorial directors of special education. In addition, since approximately sixty percent of 89-313 funds are expended on behalf of mentally retarded children in state institutions and other eligible settings outside the public schools, the Committee's staff encouraged the National Association of Coordinators of State Programs for the Mentally Retarded to conduct a parallel survey of state mental retardation officials.

A memorandum transmitting the Education and Labor Committee's questionnaire was sent to all state mental retardation directors in early February. The findings contained in this report are based on written responses received from a total of nineteen states (see list of respondents at Attachment B). While there is no way of verifying that the replies received are representative of the views of state mental retardation officials in the non-responding states, the NACSPMR staff believes, based on its continuing interaction with state MR officials, that the results constitute a reasonable cross-section of nationwide opinion on this subject.

II. Findings

A. Future of the 89-313 Program. Three survey questions dealt with the possibility of terminating 313 aid. The first asked whether the program should be continued in its present form. The second requested a reaction to the possiblity of repealing the provison of 89-313 and, thereby, totally eliminating federal support on behalf of handicapped children in state operated and supported schools. Finally, respondents were asked for their opinions regarding the impact of combining the 89-313 and 94-142 funding authorities.

Among the eighteen state MR directors responding to the first question there was unanimous agreement that the 89-313 program should be continued, either in its present form or with only relatively minor changes. While a wide variety of reasons were cited, the concensus of opinion was probably best summarized by Dan Payne, Assistant Commissioner for Mental Retardation in the Virginia Department of Mental Health and Mental Retardation, who said:

> "The 89-313 program should remain as a separately funded program under ESEA for eligible children receiving education in state operated hospitals and institutions. The administration of 89-313 programs can more clearly be defined and controlled if the programs remain separate from those federally funded programs offered for handicapped children in local school divisions."

Although there was agreement on the need to continue the 313 program, over half the respondents (10) indicated that they felt specific aspects of the program's operation needed to be changed. The nature of these proposed changes are summarized in the section on operational problems (see II-B below).

All nineteen respondents agreed that discontinuation of 313 support would have a disastrous impact on the range and quality of educational services provided to handicapped youngsters in state operated and supported schools. The following comments exemplify the responses received:

> "A drop in some supportive services from P.L. 89-313 (like occupational therapy, physical therapy, etc.) would have a direct effect on the quality of education received by institutionalized students." (Francis P. Kelley, Director, Florida Retardation Program Office)

> "(a) Educational services at Waimano Training School [would] be cut by 1/3; (b) 89-313 schools [would] lose educational assistance and some teachers, and [would] not be able to conduct summer school programs and provide supplemental materials and equipment needs." (William S. Fujikawa, Program Specialist, Office of Instructional Services, Hawaii Department of Education)

> "The lack of a categorical program to specifically address the supplemental needs of institutionalized and non-public educational facilities would be disastrous. The state provides only basic minimal education in these facilities, where the most handicapped

children are provided an educational program. There would be only a basic minimal education program for the most severely handicapped child." (Charles L. Leight, Assistant Director for Administration, Maryland Mental Retardation Administration)

"The occurrence. . . would be devastating to many of North Carolina's programs serving mentally retarded children through the Division of Mental Health Services. Our office currently serves 3,568 children with 89-313 funds on a budget of $1,477,687 and anticipates serving 3,169 childen in fiscal year 1978 with an anticipated budget of approximately $1,515,384. Those served include residents of four regional mental retardation complexes, and eighty developmental day centers. Approximately 100 employees would be directly effected if this funding was ceased, and thousands of dollars provided for equipment, supplies, and consultative services would be relinquished." (Tony Hannah, Educational Program Specialist, Mental Retardation Section, North Carolina Division of Mental Health Services)

"If total funding ceased it would have a dramatic and disastrous effect on programs in Oregon, specifically. Approximately 234 mentally retarded, developmentally disabled pre-school children would be dropped from service. This would affect the employment of 20 teachers and 19 teacher aids. In addition, it would reduce educational programs in the institutions for the mentally retarded by half. Oregon's Parent Training Program would be severely curtailed, as the core of the program the Teaching Research Behavior Clinic, would probably be discontinued, as would three of the 13 parent trainer positions which are currently covered by Title I. The pre-school, TMR and prevocational training program which so far has trained approximately 120 teachers in an intensive one-week inservice training program, would be severely curtailed; and finally, two consulting specialists, who offer consultation help and direct instruction, as well as providing leadership and in-service training, would be discontinued." (David A. Isom, Assistant Administrator, Oregon Mental Health Division)

"This would be a drastic blow to many of the programs and primarily the Community Day Service programs who are now addressing themselves to the 0-3 age group. Wisconsin has taken the position that the educational services for children of compulsory school age are the responsibility of the local educational agency (LEA) and we are contemplating phasing out our day service programs from providing services for children 3-5 and young adults 18-21, possibly by 1980 through a cooperative agreement with the SEA which would conform to the intent of P.L. 94-142 . . ."

"The cessation of these funds coming into the state, needless to say, would have a severe impact on the educational programs within state residential facilities under DHSS . . . The funds available through state monies would enable us to maintain a level of programming that would meet the standards of the SEA but would not

be sufficient to encourage the creative and innovative kinds of program that we have been able to develop through the use of these federal funds." (Gerald E. Dymond, Director, Bureau of Developmental Disabilities, Wisconsin Division of Mental Hygiene)

Twelve respondents indicated that a diminution of services to children in state run facilities would probably occur if 89-313 funding were to be folded into the Education of All Handicapped Children Act. Most of them based this conclusion on the wide gap between the current per capita federal reimbursement rates under 89-313 and 94-142. They also expressed serious doubts concerning the capacity and willingness of the general school system to address the special educational needs of the severely retarded and multi-handicapped youngsters often found in institutional settings. Even the three respondents who expressed philosophical support for assigning the state/local educational system responsibility for educating children in institutions and similar non-LEA settings expressed some reservations about their state's capacity to do so without interruption in vital educational services to affected children.

The following extracts typify the views of the respondents:

"Lack of specific identification and priorities for children's needs who are outside of the public education sector would be detrimental to meeting the educational needs of these children. Disregard of turfdom in providing local education funds following the child regardless of where his education occurs has not been accomplished within Maryland. It would be difficult if not impossible to assure that children in institutions would receive funding appropriated through the Local Education Agency, which is the unit level of 94-142. Combining these programs would, in our opinion, submerge the needs of the most handicapped population. If these children could not be counted to immediately generate funding (this is the case presently), their current educational program would be severely curtailed." (Charles L. Leight, Assistant Director for Administration, Maryland Mental Retardation Administration)

"The programs under our control would not be guaranteed continuation since we are not considered to be a school district or part of a school district. We would not be eligible to receive direct funding on the basis of 94-142. We would still be eligible to apply for the state-controlled share of those funds but we would have to compete for them and, since the unserved have priority and our clients are generally served, we would not be in the forefront of those eligible groups. Consequently, we would anticipate a regression on the part of our clients." (Russell C. Siraguse, Director, Bureau of Education, Division of Mental Retardation, New York Department of Mental Hygiene)

"As it is currently projected, the P.L. 94-142 funds would be spread out on a per capita basis to all handicapped children in any given district. This means that each child would generate $70, $35 if

which would go to the district and $35 of which would go to the Department of Education. Currently, Oregon is generating $532 in P.L. 89-313 funds for each MR/DD child counted. The vast majority of these funds go directly back to services for MR/DD children. If this funding were spread out over all handicapping conditions, it would significantly reduce the services to the MR/DD children." (David A. Isom, Assistant Administrator, Oregon Mental Health Division)

"For the coming year the 89-313 funding level is $414.00 per child and 94-142 is $70.00 per child. This would be almost as bad as a total discontinuation." (James E. Craft, Ed.D., Deputy Commissioner for Mental Retardation Services, Texas Department of Mental Health and Mental Retardation)

"It is estimated in Virginia that combining 89-313 money with Public Law 94-142 would drastically reduce the amount of per pupil allocation that would be received by mental retardation facilities for project year 1977-1978. The projected per pupil allocation for next year would be $649.00 for 89-313 as opposed to $30.00 per pupil allocation as figured under Public Law 94-142 for 1978. Such a significant reduction in funding would cause considerable harm to the educational services now provided to eligible children under 89-313." (Dan Payne, Ph.D., Assistant Commissioner for Mental Retardation, Virginia Department of Mental Health and Mental Retardation)

"This may be one of the better alternative, in that the dichotomy between institutional programs and public school programs would be minimized. Since the SEA already administers both programs, it seems logical to have single legislation to cover all handicapped. However, it is important to consider that such a combination might cause a reduction in funding levels for P.L. 89-313. Currently, P.L. 89-313 generates about $450 per child whereas P.L. 94-142 is expected to provide much less." (Francis P. Kelley, Director, Florida Retardation Program Office)

B. Current Operating Problems. Respondents were asked to identify problems surrounding the current operation of the 89-313 program and whether these difficulties were attributable to provisions of the statute, implementing regulations, state jurisdictional boundaries etc. While a variety of problems were pointed out, the overall impression one received was that the respondents viewed these problems as administrative impediments to the smooth functioning of the program rather than fundamental structural weaknesses in the legislation or its underlying philosophy.

The two most frequently cited problems were the operation of the so-called deinstitutionalization authority and several concerns which could be loosely categorized as ineff cient or ineffective federal management. Comments concerning the deinstitutionalization authority will be summarized in the next section of this report (see II-C below).

Four respondents cited the delay in issuance of final, revised regulations to implement 1974 amendments to the statutory authority for the program as a major administrative impediment to progress. Francis P. Kelley, Director of the Florida Retardation Program Office, summarized the views of these states when he said:

> "One of the major problems in the operation of P.L. 89-313 stems from the fact that there are no final rules and regulations from HEW. One of the proposed rules changes (116 b.87), which states that parents may not be charged for any services including room and board, conflicts with SS.394.457(7) and 393.09, Florida Statutes, which allow for maintenance of clients' charges."

A closely related problem referred to by two states is the lack of flexibility in current operating policies and procedures. As one respondent put it,

> "In attempting to follow the State Department of Education interpretation of the use of 313 funds . . . many basic education programs have not been started, and some creative programs have had to be delayed because regulations were lacking. The opportunity to offer direct instructional services to several facilities now eligible for 313 funds has been curtailed by the inflexible interpretation of the supplemental services definition." (Dan Payne, Ph.D., Assistant Commissioner for Mental Retardation, Virginia Department of Mental Health and Mental Retardation)

Three states also referred to the protracted delays in issuance of federal grant award notices as a source of difficulty in maintaining program continuity and encouraging innovation. "The only problem we have had", one respondent remarked, "concerns the Bureau for the Education of the Handicapped's delay in getting funds to the State Agency. Although Congress has authorized advance funding, there has been a consistent delay in B.E.H. getting the letter of credit to the state before July 1. State agencies which do not have reserve funds must delay starting the project until the funds are received." (James E. Craft, Ed.D., Deputy Commissioner for Mental Retardation Services, Texas Department of Mental Health and Mental Retardation)

Other problems alluded to by the respondents included: (a) the current restrictions on the age of the individuals served in 89-313 programs (3); (b) the lack of clarity concerning the role of the SEA and the state agency responsible for operating federally funded programs (3); (c) the lack of administrative funds (2); (d) the rigid interpretations concerning targeting programs on children included in the 89-313 count (2); and (e) the difficulty in assuring that children are not "double counted" under 313 and 142(2).

The following excerpts typify the comments on the above topics received from the respondents:

> "A problem that is attributable to the law, and one that is becoming progressively more serious, is in relation to the fact that education for a severely or profoundly retarded person can-

not stop when he or she becomes 21 years of age, as does the funding under 89-313." (Gareth D. Thorne, Commissioner, Connecticut Department of Mental Retardation)

"Currently, though there is not a lower age limit in the Special Education law of the State and the Raines decree refers to all children, 313 programs only permit, as countable for funding, children age 5 through twenty. This hampers provision of supplemental services to children who are in an early education program. It would be our recommendation that 313 funds provide for supplemental services to handicapped children in approvable projects as opposed to age level and permit the count of these children in order to generate funding, when enrolled in an approved educational program." (Charles L. Leight, Assistant Director for Administration, Maryland Mental Retardation Administration)

"[T]he primary problems that exist in our state are attributable to the state administrative jurisdiction that exists . . . [T]here is too much autonomy being given to the state agency without some form of appeal process that the participating agencies can utilize in the event that they are not in complete accord with the interpretations or decisions that are rendered."

"For example, we currently are not in accord with some interpretations being applied. We have placed calls and submitted correspondence to Washington regarding these concerns and at this date, after a period of eight months, have had no response to our correspondence . . ." (Gerald E. Dymond, Bureau of Developmental Disabilities, Wisconsin Division of Mental Hygiene)

". . . [W]e should again be allowed to 'concentrate on the needs of a limited number of children'. Targeting or focusing on selected groups of few has greater impact that a generalized effort to serve all equally." (Maurice A. Harmon, Director, Washington Bureau of Developmental Disabilities)

"As you are aware, children counted under 89-313 may not be included in the count for P.L. 94-142, therefore confusion centered around 'who may count whom for what' will most likely become problematic." (Tony Hannah, Education Program Specialist, Mental Retardation Section, North Carolina Division of Mental Health Services)

C. Deinstitutionalization Authority. The respondents were asked how well the provision of the 1978 amendments, which permits 313 funds to be passed through to LEA's on behalf of deinstitutionalized children, has worked in their states.

Most of the respondents (11) agreed that the so-called deinstitutionalization authority has had little or no impact on getting inappropriately

placed children out of large residential care facilities and many felt that the administrative headaches involved far outweighed any theoretical advantages of retaining this provision as part of the statute. Some state officials also alluded to the funding trade-off which occurs when 313 monies are transferred to LEA's - i.e., reduced services to children in 313 programs - and questioned the social utility of such a policy in view of the federal/state/local funding base currently available to handicapped children served in local public schools.

The following are a representative sample of the comments received on this subject:

> "The State Department of Education subtracts money from the allocation given to the Department of Mental Retardation each year to cover the expense of those former residents who have moved on to public school. Although 72 children left our programs during the period October 1975 - September 1976 to enter L.E.A.'s, this transition was made possible because of the progress the children achieved in their institution classes, and not because of the provision for pass through of funds." (Gareth D. Thorne, Commissioner, Connecticut Department of Mental Retardation)

> "The provision which allows P.L. 89-313 funds to pass through LEA's providing education to former residents of state institutions does not work in Louisiana. While there are 16 projects serving some 250 children in LEA programs, not one child has been deinstitutionalized as a result of this provision. The vast majority of these children are transfers from Day Developmental Training Centers (a state supported program)."

> "Most children become transfers to LEA programs through administrative change required by state law which mandates the LEA's provide educational service for handicapped children. Many times the child, already in the least restrictive environment, remains in the same program, in the same building with the same teacher. While this is in keeping with the law, it is clearly not deinstitutionalization. This provision should be explicitly eliminated from P.L. 89-313." (Otto P. Estes, Assistant Secretary, Office of Mental Retardation, Louisiana Health and Human Resources Administration)

> "This is a poor mechanism at best, particularly in the light of program planning. We could not say that children have been deinstitutionalized because of this mechanism. Again, turfdom which does not affect our regionalized institutions is a problem regarding education for children in a LEA. Also attendance in a day public school program is not deinstitutionalization.

> "Institutional schools are unique and in Maryland have a plethora of knowledge in programming for these multi handicapped children. Though our major priority is deinstitutionalization, we have a deep concern that the children be appropriately placed and that

the programs initiated by the LEA operates for a sufficient number of days so that institutional care requests will not increase. Through the supplemental programs such as 313, institutional schools operate on a twelve month cycle." (Charles L. Leight, Assistant Director for Administration, Maryland Mental Retardation Administration)

"The pass-through of funds through LEA, to my knowledge, is only one year old in this state; last year seven children were able to claim that money and I understand that less than half of the districts, in fact, claimed it. This year, there were approximately 35 eligible children. We are not aware that this minor amount of money has any effect whatsoever on whether a child will or will not be deinstitutionalized. That question is more likely to be answered, not by the school district's ability to provide appropriate programs, but by there being appropriate living conditions outside the institution." (David A. Isom, Assistant Administrator, Oregon Mental Health Division)

"There is one change we would like to see made in the 89-313 Act. It concerns the 'Money Following the Child Provision' (Section 121d). In our state it has been almost impossible to implement this provision of the Act for the following reasons:

(a) After a child leaves one of our institutions it is very difficult to maintain a continuous follow-up. We can not verify if the child is entered in an appropriate Special Education Program. We are presently trying to solve this problem but no solution is in sight because of confidentiality and other privacy rights requirements that we must adhere to.

(b) Unless a school district has a large number of former 89-313 students, it is not administratively or economically feasible to go through the application and report requirements for such a small amount of funds. We have found a large major[illegible] of the funds that were set aside are not applied for.

(c) There is no limitation on how long a former student remains eligible for 89-313 after they leave our institutions.

It is our recommendation that this provision should be dropped from the Act." (James E. Craft, Ed.D., Deputy Commissioner for Mental Retardation, Texas Department of Mental Health and Mental Retardation)

"The minimum amount ($399.38) of money that flows to LEA's under 313 has not proven significant in Virginia to create a mass deinstitutionalization movement on the part of LEA's that would

receive 313 monies if children were returned to them. Also, the primary reason in Virginia for institutionalization in mental retardation facilities does not center around the fact that children require an educational program, but it involves a multiplicity of factors that encompasses the total child." (Dan Payne, Ph.D., Assistant Commissioner for Mental Retardation, Virginia Department of Mental Health and Mental Retardation)

"[T]he provision has not worked within our state and I feel the federal government is probably about two to three years behind in determining how much money should be withheld to go back into the LEA's. Here in Wisconsin the majority of our youngsters within our state residential facilities for the developmentally disabled are at the severe and profound level; therefore, not as many will be returning as have in the past nor as rapidly, yet the amount of money that is being retained for this purpose to follow the youngster into the LEA is still at an unusually high level. In Wisconsin it has been $400,000.00. I really think this is an exorbitant amount and needs to be adjusted downward to accommodate the changing population and to recognize the fact that there are not going to be as many youngsters returning to the community as rapidly as they have been in the past."

"How many children have been deinstitutionalized as a result of this; I really cannot say that P.L. 89-313 funds is the basic cause of children being returned to the community. I think it is a variety of variables occurring that enable us to move along in this concept of deinstitutionalization . . . I think it is . . . the attitude of the community and the state of the art at this particular point in time that enables communities to gear up and provide programs and services for these youngsters upon their return to the community. I think another major factor is the development of the group home or foster home concept that enables movement of youngsters from the state residential facilities into these kinds of facilities within a community that has moved ahead in developing services to accommodate youngsters. Nevertheless, through the availability of these funds the kind of programming introduced has certainly contributed to the overall development of these youngsters so that they can participate in a group home setting. It is one part of a total treatment package that exists within state residential facilities that enables the youngster to return to the community." (Gerald E. Dymond, Director, Bureau of Mental Retardation, Wisconsin Division of Mental Hygiene)

D. Use of 313 Funds. A series of questions were raised about the use of 313 funds and other alternative sources for supporting educational programs in state operated and supported schools.

Asked whether current state appropriations cover all educational costs of children in state supported institutions, most respondents (8) answered affirmatively. However, when the responses are examined more closely one finds that almost all of the respondents, whether responding negatively or positively to the question, were saying roughly the

same thing: the state covers only the basic costs of educational services and, given the needs of these severely handicapped children, the supplemental services financed through 89-313 funds are absolutely essential. In other words, the way the question was phrased, did not lend itself to a simple "yes" or "no" answer. This point is illustrated in the following two excerpts:

> "A basic educational program is provided by the State in state supported institutions. The definition of "all educational expenses" is a question of interpretation. I included in this statement is medical and paraprofessional support services e.g., speech, physical and occupational therapy, psychological services, remedial teachers, etc., to the full extent necessary by the child's prescriptive needs, we would have to answer negatively. The state supports a basic education program in the institution. Supplemental grants provide other services." (Charles L. Leight, Assistant Director for Administration, Maryland Mental Retardation Administration)

> "Definitely not. They cover basic educational expenses but . . . one must recognize with the recent enactment of the mandatory special education law, which is only three years old, we have been put in a position of not being able to meet the needs of the youngsters in appropriate programs in every instance." (Gerald F. Dymond, Director, Bureau of Mental Retardation, Wisconsin Division of Mental Hygiene)

Most of the respondents (14) indicated that the preponderence of 313 funds are being used to provide direct services to mentally retarded children. However, here again, it was evident from the tenor of the replies that the respondents were using different operational definitions of the terms "direct" and "indirect" services. As a result, some of the illustrations cited by those who reported that a significant portion of their state's 313 allocations were being used for "indirect" services were almost identical to those given by respondents who said their state was using the funds for "direct" services. In reality, it appeared that most of the states were using 313 funds for services to children which would be best classified as supplementary to the child's basic educational program.

Those respondents who felt able to answer the question agree that other state agencies which they were familiar with were using their portion of the state's 313 allocation in roughly the same manner as the state MR agency. About forty percent of the respondents, however, indicated that they were not sufficiently conversant with the activities of other state 313 agencies to respond to the question.

The respondents were unanimous in reporting that 313 funds were being used to supplement and not supplant other state and local sources of funding for educational services to children in 313-supported programs. All of the respondents who replied to the question also indicated that federal funds are maintained in a separate account so they can be readily audited. "As the legislature authorizes increasing state general funds," one respondent said, "the state general funds are used to replace the

313 funds, which are then reallocated to new programs or to increase the services to existing programs."

In general, the respondents also agreed that 89-313 funds in their states are being targeted on the children included in the 313 count. However, a few state officials noted that it becomes impractical to apply this rule too rigidly in instances where new children are admitted to programs or programs serving 313 children fail to apply for grant support (but, nonetheless, are providing appropriate educational services to enrolled children). For example, one state official noted:

> "In all honesty we must say individuals who have been counted may not be receiving the benefit of P.L. 89-313 funds. The reason this has occurred is that the agency who submitted an ADA count for any one of several reasons may have decided not to submit an application for the use of these funds. Therefore, we do find ourselves in this kind of position. Nevertheless, those individuals, if they were counted and are not receiving benefits from any P.L. 89-313 funds at this particular time, are being provided programs in the day service agency or have been transferred to the LEA and are receiving an appropriate educational program. In essence, although the intent and the direction is to use the money for children who generate it, there are instances where this is impractical and by the same token should not be a hinderance to other eligible children in eligible programs to utilize the funds." (Gerald E. Dymond, Director, Bureau of Mental Retardation, Wisconsin Division of Mental Hygiene)

In response to the request for specific examples of how 313 funds were being used, the respondent sent in a variety of illustrations - some of which were general illustrations of the types of projects funded and others of a more specific nature. It is beyond the scope of this report to attempt to summarize or categorize the nature of the responses. Suffice it to say that the examples provided tend to illustrate the wide range and diversity of educational services being funded under 313 and the basic supplemental thrust of the program.

III. Conclusions

The following general conclusions can be drawn from the above analysis of the survey responses:

- Handicapped children in state operated and supported schools have derived tremendous benefits from the Title I ESEA program since it was initially authorized by Congress in 1965. In many cases the severely retarded and multiply handicapped youngsters who are benefiting from the program were previously denied access to any education and training services. Instead, they were left to wile away their lives at home or in the back wards of large, sterile state institutions. In many state-run facilities, Title I aid has been the single most important impetus to the initiation and expansion of educational programs for severely handicapped youngsters.

- Continuation of a separate, identifiable program of federal assistance on behalf of children in state supported facilities is absolutely essential - at least for the foreseeable future. Despite the passage of P.L. 94-142, with its strong emphasis on a zero reject educational system, the quality and scope of programs for children in most state operated and supported facilities would suffer if Title I benefits were folded into Part B of the Education of the Handicapped Act at this point in history. This conclusion is clearly documented in responses to NACSPMR's recent survey. The most frequently cited reason for anticipating a decline in federal support was the likelihood that SEA's and LEA's, under a consolidated program, would sharply reduce the current level of federal aid flowing to state supported schools - especially in view of the wide discrepancy in per capita aid levels under the Title I and Part B programs. One also wonders whether Congress would be willing to approve the same level of funding for a consolidated program as it would for separate programs - particulary considering the sharp increases contemplated in Part B funding. Finally, the fact that, in a majority of states, legal responsibility for providing educational services to children in state schools still rest with an agency or agencies other that the education department suggest that consolidation might further complicate interagency relationships at the state and local level when they already are undergoing severe strain.

- There is a need to improve the legislative and administrative interface between Part B and Title I programs. Among the specific issues referred to by the respondents to the recent NACSPMR survey are: (a) differentiating between the Title I and Part B counts of eligible children; and (b) identifying the circumstances under which parents can be hald financially liable for the non-educational costs (i.e., room, board and medical and related care) of Title I eligible youngsters. Another issue which must be considered is fixing responsiblity for case management and service delivery on behalf of multi-handicapped youngsters residing in Medicaid-eligible long term care facilities (were both an individualized education plan and an individualized habilitation plan must be prepared on the child).

- The "deinstitutionalization" incentive, built into the 1974 amendments to Title I, needs to be either eliminated or sharply modified. As indicated above, many of the survey respondents indicated that the 1974 provision has had little or no impact on the placement activities of public institutions. Indeed, because of the Title I hold harmless language adopted by Congress that same year, the deinstitutionalization incentive has resulted in resources being drained away from state-run facilities to reimburse local school districts. Obviously, this process of "robbing Peter to pay Paul" does little to accomplish our overall goal of assuring that all handicapped children receive the appropriate educational services they need at the earliest possible date.

Robert M. Gettings
National Association of
Coordinators of State
Programs for the Mentally
Retarded, Inc.

April 22, 1977

APPENDIX C

FACT SHEET

on the

Federal Technical Assistance Grant Project

Title: The Provision of Technical Assistance on Federal Programs of Significance to the Developmentally Disabled

Grantee: National Association of Coordinators of State Programs for the Mentally Retarded, Inc.

Granting Agency: Developmental Disabilities Office, Office of Human Development, Department of Health, Education, and Welfare

Statutory Authority: National Significance Grant awarded under Part D of the Developmental Disabilities Services and Facilities Construction Act, as amended

Project Period: October 1, 1976 - September 30, 1978

Funding: $169,013 in FY 1977 and $180,120 in FY 1978

Background: Over the past decade, federal assistance for financing residential and community based programs for the developmentally disabled has been rapidly expanding. The major portion of the increase has come, not through categorical grant programs, but rather as a result of expanded eligibility for assistance under federal health, social services and welfare programs. However, despite the inroads which have been made, participation by developmentally disabled individuals in many generic assistance programs is still limited, largely due to: (1) the lack of clear, accurate information concerning the benefits which developmentally disabled persons might derive from such federal programs; (2) the existence of barriers (often unintentionally erected) to participation by the developmentally disabled due to a failure to understand the specialized needs of this target population and lingering misconceptions about their capabilities; and (3) statutory, regulatory or administrative policies which exclude or greatly restrict the participation of certain developmentally disabled persons.

Project Objectives: The overarching goals of this project are: (1) to expand the benefits available to developmentally disabled persons through federal human service programs; and (2) to demonstrate a conceptual approach to providing technical assistance which will help both consumer advocates and service providers to make better use of generic federal assistance programs.

In order to meet these goals, the following basic objectives have been established for the project:

- to provide clear, concise, readable information about the implications for developmentally disabled persons in the generic federal assistance programs selected for study;

- to identify the policy barriers to fuller participation of the target population in such programs;

- to develop collaborative strategies for eliminating such policy barriers through the joint action of national, state and local organizations interested in the developmentally disabled;

- to furnish written and audio-visual materials which can be used by interested professional and citizen groups to bring existing impediments to full participation of the developmentally disabled to the attention of key federal administrators in generic service agencies.

Project Methodology: The project will be conducted in seven carefully sequenced phases. During the initial, gearing up phase of the project, staff will be hired, suitable office space located and necessary office furnishings and equipment purchased.

Three federal program areas will be selected for intensive study during the second phase of the project, based partially on the results of a structured series of telephone interviews with service providers and consumer representatives across the country. In addition, a summary of relevant policy issues, selection criteria and a strategy plan for gathering, synthesizing and summarizing relevant issues will be developed during this phase of the project. Three target federal regions and two states within each region will be identified for in-depth analysis during the following work phase and specifications for a contractual study will be developed.

During Phase III a contractual agency will be selected to conduct a study of intra and inter-regional barriers to the fuller participation of developmentally disabled persons in the three selected federal program areas. The purposes of this study will be to: (1) identify and classify the types of problems faced by service providers in attempting to utilize available resources in the three federal program areas; (2) differentiate between barriers associated with national, intra-regional and intra-state policies and analyze emerging patterns across state and regional boundaries; (3) recommend approaches for overcoming identified barriers; (4) describe any inconsistencies in policy interpretations across regional boundaries and suggest methods for minimizing such inconsistencies; and (5) assist in identifying and implementing collaborative strategies for bringing issues to the attention of responsible federal regional officials.

Materials on the first federal program area will be developed during Phase IV of the project. After gathering and analyzing relevant information from diverse sources, an issue paper will be prepared to delineate how participation by the developmentally disabled might be increased. Later, a slide/tape presentation will be developed and widely distributed among provider and consumer groups to assist them in understanding

how to access the resources of the particular federal program and overcome identified federal policy barriers. Finally, in collaboration with other interested organizations, a multi-faceted strategy for promoting use of the particular federal program will be developed and implemented.

Phases V and VI of the project will repeat essentially the same steps used in Phase IV only with the focus shifted to the second and third federal program areas. The two year project will be drawn to a close with an analysis of evaluative data and the preparation of a summary report (Phase VI).

The entire project will be carried out with the assistance of a ten member Project Advisory Board. This Board will consist of representatives from key member organizations of the Consortium Concerned with Developmental Disabilities (National Association for Retarded Citizens, National Society for Autistic Children, National Association of Coordinators of State Programs for the Mentally Retarded, United Cerebral Palsy Association, National Easter Seal Society, Epilepsy Foundation of America and the National Association of Private Residential Facilities for the Mentally Retarded) plus two selected representatives of state developmental disabilities planning councils. In addition, from time to time, representatives from other national organizations will be asked to participate in the Board's deliberations when they have a particular interest and expertise in the federal program under discussion. By involving consumer, provider and professional interest groups in the design and execution of the project, it is hoped that the staff will be able to achieve a much broader distribution of written and audio-visual materials and develop more realistic and targeted implementation efforts.

Project Director: Robert M. Gettings, NACSPMR Executive Director

Senator STAFFORD. The Chair would ask Dr. Elizabeth Boggs to take the witness stand.

STATEMENT OF ELIZABETH M. BOGGS, Ph. D., HAMPTON, N.J.

Dr. BOGGS. Thank you, Mr. Chairman.

Senator STAFFORD. Thank you, Dr. Boggs.

If you have a prepared statement——

Dr. BOGGS. My prepared statement will be typed and delivered a little later in the day. It is being duplicated.

Senator STAFFORD. I must point out that under Senate rules this committee will be forced to recess not later than 11:30.

Dr. BOGGS. I hope to abbreviate my remarks and rely on the full statement in the record.

I do appreciate this opportunity to appear as an independent individual who has been participating in a number of aspects of the DD program, in recent months, and I hope to bring some new perspectives on it.

Before going further, I do want to commend and thank the committee for its concern as expressed in its 1978 budget proposal of $69 million for the overall program. This is very encouraging and suggests to us that you have confidence in the program.

By way of general introduction, I want to report to you that I think the developmental disabilities movement is in surprisingly good shape, considering the vicissitudes to which it has been subjected.

It has undergone some major structural changes at both the State and National levels during 1975–76. It is in the process of launching the protection and advocacy systems, and there is considerable enthusiasm around the country for doing this.

Deinstitutionalization is proceeding apace. I happened to pick up some figures from region IV, which covers the deep South, and I thought you would be interested to know that the rate of resident population in those States is now only 64.03 persons per 100,000, as compared to 71.14 nationally and represents a spectacular decrease from the national average of 10 years ago, which was close to 100 per 100,000.

The Developmental Disabilities Office has instituted an overall data gathering format. There are clearly some shakedown problems with this. I hope the initial frustration that the States planning staff have experienced will not be allowed to obscure either the merits or the deficiencies of these procedures.

I have made some suggestions about that in my statement.

The definitional study is underway. I think that the quality and caliber of the people who agreed to serve on the task force shows great interest in the subject matter. Additional groups "want in" on this program: Thus it is clearly seen as having some significant and unique potential.

Extensive deliberations, supported by several interesting studies of specifics, have resulted in a package of recommendations for the future of the UAF program. I think you have the report of the long-range planning task force and I commend its suggestions to your careful study.

Several projects of national significance which were inaugurated several years ago are beginning to bear fruit. One of these, for example,

is producing people with training in administration; this is at the UAP in Alabama. A number of the people who have gone through this program are now being promoted rather rapidly through the system, showing the usefulness of this kind of study.

The Accreditation Council, which continues to be supported under part D of the act, is moving forward with a revised and consolidated set of standards bringing together both the residential and nonresidential programs standards.

I have a few specific recommendations. These recommendations are directed toward things that I think could be initiated now in anticipation of whatever changes you may make as you proceed with the extending legislation, which we trust you will do in a timely manner.

It seems to me that it is necessary to increase the funding, particularly in the formula grant components.

Mr. Jackson Andrews, who is with you there, pointed out in the meeting in region II the other day, that the way things stand, there is a disproportionate emphasis on the discretionary funding in this program as compared to other comparable programs that include discretionary funds intended to support a State formula grant. I have some suggestions as to how better balance might be achieved.

(See table in prepared testimony.)

I particularly would like to urge that the program be given a chance to stay on course for a reasonable length of time, say, 5 years through 1981, thus stabilizing the DDO mission and assuring that the States' investments in plans and procedures and in public interpretation have some durability and hence credibility. When we talk about long-range planning, and then change the plan, turn it inside out every 2 years, it is not very efficient.

I also would propose that we anticipate consolidating all the discretionary funds in one authority under which it would be possible to do all those things that are done under several different authorities. I foresee that as being a generally more accountable way of proceeding to accomplish the goals for those programs, which I think we all share.

I believe that the committee was quite right in pressing HEW to relocate DDO as a separate agency in OHD and I believe that move should be supported and retained. I believe that the reorganization of HEW which has recently taken place, which adds title XX to the Office of Human Development, reinforces that view. DDO—represents, that portion of the disabled population most in need of social services. This population is at great risk of social dependence, which is a primary focus of title XX of the Social Security Act; thus the juxtaposition should permit the Assistant Secretary for Human Development to receive concurrent input from the agencies charged to advocate for children, for the aged, and for the most severely disabled, with respect to the priorities in her two big operational programs, social services and rehabilitation.

We believe that the Ford administration proposal to fold DD into a health block grant should be laid to rest along with the recurring suggestions to subordinate the DD program to the rehabilitation program. Neither of these suggestions is consistent with the organizational structures at the State level. Few people at the Federal level realize that the MR/DD programs in the various States already exceed the rehabilitation programs in volume by several fold.

We fully believe that this subcommittee, with its House counterparts, should reinforce the efforts of those advocacy groups which are attempting to implement section 111(4)(a) of the act requiring application of standards in residential facilities which "are at least equivalent to those standards applicable to intermediate care facilities for the mentally retarded promulgated in regulations of the Secretary on January 17, 1974." These regulations were scheduled to go into effect 2 weeks ago. Their effective date has been postponed and there is serious threat that they will be diluted in response to pressure from the State Governors. This pressure emanates particularly from those States whose receipt of Medicaid funds under this heading, that is, ICF/MR, has done more to refinance State deficits than to benefit the residents of public and private facilities.

There is an immediate need to increase the resources prospectively available to the Protection and Advocacy Systems beginning with fiscal year 1978, the first operational year. You will recall that there was a $3 million authorization for all 3 years—(1976, 1977 and 1978). But, 1978 is going to be the test year because that is when they are mandated to begin.

I agree with the position set forth by the leadership of the subcommittee in its letter to the DDO Director, Francis X. Lynch, dated November 1, 1976, that these systems should seek and secure multiple funding, including funding from the State DD formula grant. In fact, in my home State of New Jersey, which I believe has the distinction of being the first to complete planning, and go operational with protection and advocacy, we have approximately doubled the funds available to it in this way, using 1977 DD formula funds.

However, at present levels of formula funding, this assistance, means a sacrifice in other areas. Moreover, in many States this funding could be made available only with the concurrence of the administering agency in charge of the design for implementation. This is an agency of which the protection and advocacy system is mandated to remain independent. There is a need to assure independent "core support" through specific authorization under section 113(b)(2).

It occurs to me, as I am sure it has to you, that additional funding could still be made available in 1978 by a simple amendment to this section, which we might be able to carry along with some other legislation that you would have under consideration. At present the small States receive proportionately more than the larger ones and I would recommend that there be an understanding that this increase, if achieved, be pro rated among all the States in accordance with their present allotment under this Section. This would increase the allotments to so-called minimum allotment States along with the others.

There is a need to address the underlying "504 problem" realistically. The problem hinges on the extraordinary and unbudgeted expenses which could be imposed on providers, especially higher education facilities, in retrofitting and remodeling. So far as the universities, and university affiliated facilities are concerned this should be accomplished generically, outside the Developmental Disabilities Act or any other specific program for professional training, such as health manpower, vocational rehabilitation training and so forth. It seems to me that this subcommittee could use its good offices with the Education Subcommit-

tee to authorize, on an urgent basis, construction funds to universities and colleges, for this express purpose.

I frankly feel that putting a small construction program through DDO at this time would only exacerbate the burden of many small mandates with which it is already struggling.

I believe, also, that the satellite concept should be approached in a less arbitary manner. This shift should take place in the fiscal year 1978. I think advantage should be taken of new options coming on the scene, especially the Carter administration's proposed expansion of comprehensive child health programs to provide support to the clinical service components which satellites are expected to offer.

If the developmental disabilities child got only 10 percent of the benefits of that proposed program, it would exceed anything that we could hope to do under the proposed satellite service funding.

I have studied the excellent paper by Mrs. Forsythe and Dr. Moss, covering some of the history of UAF involvement in clinical services. They rightly point out that training has been the mission for which UAF's were originally funded, first by the mental retardation branch in the mid-sixties, and later through section 511 of the Social Security Act. It has been the intent that training be conducted in exemplary settings, especially for interdisciplinary clinical programs as described in Senate report 94–160. However, the actual support of the service components has been from the beginning, and even before 1963, drawn primarily from those sources available to support such services in other settings as well, that is maternal and child health and crippled children's service funds.

Service funding in UAF's under part B of the Developmental Disabilities Act, beginning in 1972, was authorized only for operating demonstration facilities and very little money was, in fact, available for this purpose.

In the case of clinical service programs for mentally retarded and crippled children, the most successful program, measured by outreach and accessibility, have been those which received major support through State administered and matched maternal and child health and crippled children's funds. Two of the most impressive statewide networks, those in Washington State and North Carolina, are piloted by UAF's as backup centers but the funding of the in-State satellites was and is, provided through the States' health agencies. I might say there is an excellent article describing the Washington system which I will make available to the committee. This is in accord with the thrust of the Developmental Disabilities Act to access and augment State level mechanisms and involvement of major State agencies which have an ongoing responsibility for seeing that services are available and accessible within the State.

By contrast, the model presented in section 121 mandates in effect that initial action be taken across State boundaries and furthermore, really prohibits development of tertiary UAP resources within the States which do not already have a UAP. It prohibits their having within their own States the backup needed for a satellite. It also does not encourage satellite development within States having UAP's.

It is possible that in a few atypical situations, studies, a rural State without a university based medical school, this inter-State model is suitable. In many States, even the small ones that I know of, such as

Vermont and New Hampshire, both of which have first-class medical schools, the model of intra-State development would be more suitable. I think that consultation and technical assistance across State lines is appropriate, but to make urgently needed expansion of the existing UAP program contingent on a 40-percent set aside for satellites, prejudices the interests of both the haves and the have nots in this area.

Consistent with these various suggestions, Mr. Chairman, I have formulated a possible alternative strategy for distributing $69 million of 1978 funds. (See table in statement.) The effect of this would be to slightly increase the regular State formula grant. It also proposes to increase the P. & A. line. If it is not possible to increase the authorization then I would add more to the regular formula. I would place greater emphasis on the part D special projects, pushing those dollars up to the maximum authorized, with the understanding that under that general heading, both satellites and UAP development would be sponsored in a manner which can be done selectively, so as to maximize the advantages of the program.

I will make my prepared statement available to the committee and I thank you very warmly for including me on your agenda.

I hope I made it to 11:30.

Senator STAFFORD. You did very well.

You left me 30 seconds.

Thank you for coming here and helping the committee.

Any material that you have that you think would be helpful in the record, we will, without objection, make a part of the hearing record, and any expansion of your statement that you wish can be made a part of the record, too.

Dr. BOGGS. I will see that it is delivered later in the day.

[The prepared statement of Dr. Boggs and information referred to follows:]

TESTIMONY

On

DEVELOPMENTAL DISABILITIES PROGRAM

Respectfully Submitted to

THE SUBCOMMITTEE ON THE HANDICAPPED

Of The

COMMITTEE ON HUMAN RESOURCES

UNITED STATES SENATE

Presented by:

Elizabeth M. Boggs, Ph.D.

Thursday, March 31, 1977

I appreciate the opportunity to appear before this distinguished committee which has done so much to promote the well being of all the handicapped, among whom the developmentally disabled are often the least visible, and in most need.

It is my purpose here to use an eclectic perspective. In doing so, I represent no one interest while drawing on my participation in a number of DD related activities, not only in my own state of New Jersey, but in a number of other state or regional settings as well. Time permitting, I will touch on state councils and the state formula program, advocacy and "rights," deinstitutionalization, the definition, future roles for UAF's overall funding, and organizational arrangements.

Before going further, may I commend and thank the committee for its concern as expressed in its 1978 budget proposal of $69 million for the overall program.

GENERAL OVERVIEW

- Considering the hand-to-mouth character of most of its existence, the DD movement is in surprisingly good shape.

- It has absorbed some major structural changes at both the state and national levels during 1975-76.

- It is in the process of launching the protection and advocacy systems, entailing the testing of a number of new concepts. In this connection, the cooperation of the staff of the National Council of State Governments in initiating some orientation for gubernatorial representatives should be noted with approval.

- Deinstitutionalization is proceeding apace. By way of

example, some late figures made available to me from Region IV indicate that not only does the deep south already have a rate of resident population (in public institutions for the retarded) of only 64.03 persons per 100,000, as compared to 71.14 nationally, but that further decreases are in progress. These rates can be compared with a national figure close to 100 per 100,000 only 10 years ago.

- The Developmental Disabilities Office has instituted an overall data gathering format (DDEIS) which, while primitive in several respects, permits some provocative questions to be raised. The state planning staffs had only a few weeks from the time final guidelines were issued to implement the required reporting system late last summer, although training in the conduct of the system was offered four months previously. Initial frustration and inconvenience to state planning staff should not be allowed to obscure either the merits or the deficiencies of these procedures. My own view is that a major deficiency lies in the failure to distinguish between "need" and "demand," i.e., the difference between the number of persons estimated to be potentially eligible for a service and the number who would actually avail themselves of it if it were offered. Overestimates of service gaps and fiscal gaps are likely to occur. The data is still not reliably aggregatable on regional and national levels.

- Because of the great need to have more reliable specific program data on a national basis, not only on population movement into and out of public institutions, but also on the movement and circumstances affecting persons outside those settings, a project

of national significance has been awarded to the University of Minnesota to develop a protocol adapted to measuring current trends in current terms. Some indication of the needs in this area are revealed in a BEH-funded Abt Associates study tracking some 440 persons who were recently deinstitutionalized in various parts of the country.

- Extensive deliberations, supported by several interesting studies of specifics, have resulted in a package of recommendations for the future of the UAF program. The report of the Long Range Planning Task Force is now available. Recognizing that programs, rather than facilities, are at the heart of this matter, the term "University Affiliated Program" (UAP) is replacing the acronym UAF. Among the results of the special studies on UAP's was a finding suggesting that State Council chairpersons and planners agreed more nearly than had been supposed with the UAP directors that the primary mission of the UAP's is training of personnel qualified to work in the service delivery system, including training in clinical and other direct habilitation services. Direct services are seen as a mandatory function and responsibility of the UAP's only to the extent necessary to assure that the interdisciplinary training is of high quality as measured by subsequent performance of trainees in the field.

- Much needed training in administration is being provided by the UAP at the University of Alabama. Its Management Training Program, designed for inservice training of upper and middle management personnel in residential and non-residential systems is now available to a national constituency, having proven its worth on a regional basis.

- The definitional study has been launched. A diverse task force, representative of consumers, providers, legislators, and administrators, as well as of categorical "ins" and "outs," has started its work with enthusiasm. Congress asked for a definition which would be "appropriate"; presumably the intent was to produce a definition appropriate to the basic purpose of the Act. If the task force should fail (and I make no such prediction), it will likely be because too many members may want to change the basic purpose of the Act to encompass the 34 million or so Americans of all ages who are the alleged target of the White House Conference. The willingness of many busy people to dedicate time to the study (6 person days in 8 months) indicates an interest in the program which should send some sort of signal to Congress. This interest is further reflected in the continuing desire of additional disability groups to be included. The DD program produces less than 2% of the Federal dollars flowing directly to the target population, yet clearly a lot of people think it is important

- The Accreditation Council on Programs for the Mentally Retarded and Persons with Other Developmental Disabilities drafted a new consolidated set of standards for residential and non-residential services. The drafts are now out for expert review prior to final adoption. This JCAH-sponsored activity, which gave rise to the Committee's Title II in 1974 and 1975, continues to be supported under Part D.

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The foregoing items represent only a sampling of the wide variety of activities set in motion or accelerated by this Committee when it renewed and revised the Developmental Disabilities Act.

RECOMMENDATIONS:

1. The DD program has a very high ratio of complexity per thousand dollars expended, (a fact which should be borne in mind in evaluating central and regional office staffing patterns). A significant increase in funding, particularly in the formula grant component, would improve the administrative cost benefit ratio. Concurrently two "simplifying" steps can also be recommended:

   a) Except for correction of obvious sore points, the program should be given a chance to stay on course for a reasonable stretch, say five years (through 1981)thus stablizing the DDO mission and assuring that the states' investments in plans and procedures and in public interpretation have some durability and hence credibility;

   b) Consolidate all discretionary funds (Parts B and D) into a single authority with enough flexibility to cover major needs for regional and national programs in support of the basic state systems; part D as presently written is a good model if there is sufficient room (expanded authorization) to encompass training at all levels, demonstrations, model building and technical assistance.

2. The organizational position of DDO within O'D along side of other focal points for vulnerable groups such as OCD and AOA is a result of the advocacy of this subcommittee. It was a sound move and should be retained. The developmentally disabled (along with

the disabled aging) represent that portion of the disabled population most in need of services to combat social dependency, a primary goal of Title XX of the Social Security Act, a program recently transferred to OHD. This juxtaposition should permit the Assistant Secretary to receive concurrent input from spokesmen for children, for the aged, and for the most severely disabled with respect to the priorities in her two big operational programs, social services and rehabilitation.

3. The Ford administration proposal to fold DD into a health block grant should be laid to rest along with suggestions to subordinate DD to the rehabilitation program. Neither of these is consistent with organizational structures at the state level. Few people at the federal level realize that the combined state and federal expenditures for MR/DD programs in the various states already exceed the combined state and federal expenditures for vocational rehabilitation programs by several fold.

4. This Subcommittee, with its House counterpart should reinforce the efforts of those advocacy groups which are attempting to implement Section 111(4)(A) of the Act requiring application of standards in residential facilities which "are at least equivalent to those standards applicable to intermediate care facilities for the mentally retarded promulgated in regulations of the Secretary on January 17, 1974." These regulations were scheduled to go into effect two weeks ago. Their effective date has been postponed, and there is a serious threat

that they will be diluted in response to pressure from the state Governors. This pressure emanates particularly from those states whose receipt of Medicaid funds under this heading (ICF/MR) has done more to refinance state deficits than to benefit the residents of public and private facilities.

5. There is an immediate need to increase the resources prospectively available to the Protection and Advocacy systems, beginning with fiscal year 1978, the first operational year. I agree with the position set forth by the leadership of the Subcommittee (in its letter to the DDO director, Francis X. Lynch, dated November 1, 1976) that these systems should seek and secure multiple funding, including funding from the state DD formula grant. In fact, in my home state of New Jersey, which I believe has the distinction of being the first to complete planning and go operational with Protection and Advocacy, we have approximately doubled the funds available to it in this way, using 1977 funds. However, at present levels of formula funding, this assistance means a sacrifice in other areas. Moreover, in many states this funding could be made available only with the concurrence of the administering agency in charge of the design for implementation. This is an agency of which the Protection and Advocacy system is mandated to remain independent. There is a need to assure independent "core support" through specific authorization under Section 113(b)(2). It occurs to me, as I am sure it has to you, that additional funding could still be made available in 1978

by a simple amendment to this Section, perhaps to be included in the proposed one year extension of the various health bills. I would suggest $5 million. At present the small states receive proportionately more than the larger ones; I would recommend that there be an understanding that this increase be prorated among all the states in accordance with their present allotment under this Section. This would increase the allotments to so-called minimum allotment states along with the others.

6. There is a need to address the underlying "504 problem" realisticly. The problem hinges on the extraordinary and unbudgeted expenses which could be imposed on providers, and especially higher education facilities, in retrofitting and remodeling. So far as the universities (and University Affiliated Facilities) are concerned this should be accomplished generically outside the DD Act or any other specific program for professional training (such as health manpower, vocational rehabilitation training, etc.). It seems to me that this Subcommittee could use its good offices with the Education Subcommittee to authorize, on an urgent basis, construction funds to universities and colleges for this express purpose. Putting a small construction program through DDO at this time would only exacerabate the burden of many small mandates with which it is already struggling.

7. The "satellite" concept should be approached in a less arbitrary manner. This shift should take place in fiscal year 1978. Advantage

should be taken of new options coming on the scene, especially the Carter Administration's proposed expansion of comprehensive child health programs. The excellent paper by Mrs. Forsythe and Dr. Moss covering some of the history of UAF involvement in clinical services rightly points out that training has been the mission for which UAF's were originally funded, first by the Mental Retardation Branch in the mid-sixties, and later through Section 511 of the Social Security Act. Service funding in UAF's under Part B of the DD Act (beginning in 1972) was authorized only for operating "demonstration facilities" and very little money was, in fact, available for this purpose. It has been the intent that training be conducted in exemplary settings, especially for interdisciplinary clinical programs as described in Senate Report 94-160. However, the actual support of the service components has been from the beginning (and even before 1963) drawn primarily from those sources available to support such services in other settings as well. In the case of UAF based clinical programs for mentally retarded and crippled children the most successful programs (measured by outreach and accessibility) have been those which received major support through state administered (and matched) maternal and child health and crippled children's funds. Two of the most impressive statewide networks, those in Washington state and North Carolina are piloted by UAF's as back-up centers but the funding of the in-state satellites was, and is, provided through the state's health agency.*

* In some states the tertiary clinic program did have the advantage of direct funding for service demonstration via the federal maternal and child health program. This funding was available prior to launching of early UAF's and in some cases was critical to the choice of their locati

Money for this purpose was available in all states, although not equally well used in all states.

An excellent article describing the Washington system and the role of the UAF in it is appended. It is important to stress that this was an intrastate development. Both the UAF and its satellites are within the same state. This is in accord with the thrust of the DD Act to access and augment state level mechanisms and involvement of major state agencies which have an ongoing responsibility for seeing that services are available and accessible within the state. By contrast the model presented in Section 121(a)(2) mandates that initial action be taken across state boundaries and that funds, in effect, flow from an out-of-state university to initiate an in-state clinic, while prohibiting the development of tertiary care capacity at a university /within the state. It is possible that in a few atypical situations (e.g. a rural state without a university-based medical school) this interstate model is suitable. If so, it could be justified and supported on a discretionary basis, using Part D funds (if available). However, to make urgently needed expansion of the existing UAP programs contingent on a 40% set aside for "satellites" keeps these UAP's hostage to a concept that is not universally applicable, and is unfair to those states in which UAP's presently exist as well as to those which need and want their own.

8. The expanded budget for fiscal year 1978 -- $69 million for the overall program -- as proposed by the Committee on Human Resources

to the Budget Commitee should be supported. However, in the light of changing circumstances and in anticipation of changes that will become necessary when renewal comes up, I recommend a somewhat different distribution, as indicated in the attached table.

The first line represents a very modest 10% increase over 1977. The proposed distribution partially corrects the current imbalance between discretionary and formula funding and at least keeps the latter at substantially more than 50%. If it is not possible to increase the authorization for Protection and Advocacy, the additional $2 million should be added to the formula grant. The suggested allowance of $25 million in projects would net $7.5 million for all kinds of new projects in 1978. The $5.5 million would continue the UAP funding at its 1977 budgeted level, but when combined with the substantial increase in special projects funding opens options to meritorious UAP's. Using Section 145 authority would make it possible for DDO to do the following among others:

a) Make some experimental core grants and "topical" grants to selected UAP's to test out the concepts presented in the Long Range Task Force Report. This would be particularly useful at some of the stronger "non-constructed" UAP's;

b) Fund any promising satellite centers for which feasibility studies have been completed, directly or through the most appropriate agency within the state, in accordance with the state DD plan, not to the exclusion of university settings.

This rebudgeting can, I believe, contribute to solving many of the incipient problems alluded to earlier.

Thank you for the priviledge of presenting these views.

COMPARISON OF PROPOSALS FOR 1978 SPENDING UNDER THE DD PROGRAM

(in millions)

Section	Authorization	Purpose	Administration		Committee on Human Resources		Suggested	
131	$60	State Formula	$38.6	41.6	$32	35	$33.5	38.5
113	$ 3	Protection & Advocacy	3		3		5	
123	$21	UAF Support	5.5	16.5	10	34	5.5	30.5
127	$ 3	UAF & Satellite Remodeling	--		3		--	
145	$25	Special Projects Including PNS	11		21		25	
TOTAL			$58.1		$69		$69	

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Elizabeth M. Boggs
March 31, 1977

Interdisciplinary Clinics for the Developmentally Disabled—Washington State's Experience[1]

Clifford J. Sells
Margaret A. West

ABSTRACT. Washington State has been in the forefront in the development of local interdisciplinary clinics for the developmentally disabled. During the late 1950s and early 1960s, the Washington State Department of Health, working with county health departments, established local interdisciplinary mental retardation clinics in a number of communities. These clinics have subsequently broadened their services to include children with a variety of developmental disabilities in addition to children with mental retardation. Several case examples are presented to illustrate the types of children served and some of the advantages of local clinics for the developmentally disabled.

Washington was one of the first states to develop specialized interdisciplinary diagnostic clinics for retarded children. Prior to 1955, no diagnostic services were available to the mentally retarded outside of institutions in the State of Washington and, in fact, there were no diagnostic clinics for the mentally retarded west of the Mississippi River. The first clinic in the West for the mentally retarded, established in 1955 at the University of Washington School of Medicine, was the result of a cooperative effort between the Department of Health and the University of Washington and was developed as a demonstration service program. Subsequently, during the late 1950s and early 1960s, the Washington State Department of Health, working with county health departments, established local interdisciplinary mental retardation clinics in a number of communities.

The development of local child study clinics was based on the premise that (a) services for mentally retarded individuals require the cooperative expertise of several disciplines or professions, hence the clinics must be interdisciplinary, (b) the majority of services needed by the mentally retarded can oftentimes best be provided in the community where the individual resides, and (c) for many families it is not feasible or possible to receive services in geographically distant areas.

[1] Supported in part by the Department of Social and Health Services, Maternal and Child Health Section, State of Washington, and in part by Maternal and Child Health Services, Bureau of Community Health Services, Health Services Administration, Department of Health, Education and Welfare, Project #913.

At the present time, there are 11 local child study clinics and three regional clinics in the State of Washington. Most of the local child study clinics serve several counties, but there are some counties which are not served by a local clinic. Children with developmental disabilities residing in these counties are referred directly to one of the regional clinics. The geographical distribution of the clinics conforms almost perfectly to the diagnostic and evaluation service areas called for in the 1966 State Mental Retardation Facilities Construction Plan (State of Washington Mental Retardation Facilities Construction Plan, 1966). In terms of population, Washington ranks 22nd nationally (U.S. Bureau of the Census, 1973), but fourth nationally behind California, New York and North Carolina in the number of child study clinics (Clinical Programs for Mentally Retarded Children, 1974). Thus, Washington has a relatively large number of local clinics in contrast to a few large regional clinics, supporting the concept of providing services for the mentally retarded and developmentally disabled when feasible at the local level. The local child study clinics are supported primarily by federal Maternal and Child Health Service funds administered through the Department of Social and Health Services of the State of Washington.

The Clinics

Washington State's child study clinics initially required considerable professional consultation and assistance in their development since most of the professionals involved in the clinics had little experience working as members of an interdisciplinary team and many had relatively little experience working with the retarded. Professional consultation and technical assistance was initially provided by members of the faculty and staff from the University of Washington's Child Study Program. Coordination between the local clinics and the University's regional clinic was further facilitated in 1967 by the establishment of a consulting team from the University composed of a pediatrician, a social worker and a public health nurse who, in addition to their consulting responsibilities, function as members of an interdisciplinary team at the University.

Since the establishment of the first local child study clinic, the program has been expanded to include services for children with a variety of developmental problems including cerebral palsy, speech and language disabilities, visual impairments, epilepsy, learning disorders, emotional disorders, and behavioral disorders, as well as mental retardation. Although diagnosis and assessment are the primary responsibility, the clinic staff assumes the responsibility for developing and implementing an appropriate treatment or management program for each child evaluated. This may entail referral to other community resources or direct intervention by clinic personnel.

The core clinic team is composed of a public health nurse, a social worker, a pediatrician, and a psychologist. The public health nurse, or the social worker, is the coordinator for the team and is, in most instances, a full-time health department employee. Pediatric consultation is provided by one or more practicing community pediatricians on a fee-for-service basis. The team psychologist is often a local school psychologist who provides consultation generally on a fee-for-service basis. Additional health professionals such as community mental health psychiatrists, educational consultants, nutritionists, and physical and occupational therapists may provide consultation to the program.

Clinic Resident Data

For fiscal year 1974, a total of 1,030 residents were seen in local child study clinics in the State of Washington, representing a total of 4,460 resident visits. Although these clinics serve children to age 21, 80% of those served were less than 10 years of age. Mental retardation or other developmental delays (35%), learning disorders (23%) and behavioral disorders (20%) were the most frequent reasons for referral. Private physicians (31%), school officials (25%) and public health nurses (17%) referred the majority of children to the clinics. Clients have generally been satisfied with the services received, with more than 90% of patients surveyed expressing satisfaction with the services rendered (unpublished data).

The following cases illustrate some of the types of problems served by the local child study clinics and some of the advantages of local clinics.

Illustrative Cases

Case 1. A 2-year-old girl was referred to a local child study clinic by a public health nurse because of psychomotor retardation. She was one of triplets born prematurely at 28 weeks gestation. She required resuscitation and had a rather stormy neonatal course with frequent periods of apnea. Developmental milestones were delayed. Evaluation at the clinic revealed a probable severe sensorineural hearing loss and a significant visual deficit. A psychological evaluation revealed the child to be functioning at the 6- to 9-month level with a chronological age of two years. Child study clinic recommendations included an opthalmologic evaluation, enrollment in a preschool for the handicapped, speech therapy, additional audiologic assessment, completion of the child's immunizations, and regular public health nurse follow-up.

Young multiply handicapped children require close monitoring of their program if these children are to benefit maximally. The local child study clinics are in an ideal position to monitor programs for young multiply handicapped children and to help implement programs for these children.

Case 2. A 4-year-old boy was referred to the University's Child Study Clinic by a local child study clinic for further evaluation because of unusual behaviors, delayed milestones and emotional problems. A psychiatric consultation was specifically requested. Results of the evaluation at the University's Clinic indicated that the child had a severe behavioral problem with depressed language skills. A psychological evaluation revealed a 37-point difference between the verbal and performance scales on the WISC with a performance IQ of 108 and a Verbal IQ of 71. A 2-week placement in a special educational classroom at the University provided an opportunity for representatives from the child's community to work with the University staff in formulating a specific educational program for him. He returned to his community to be followed by the local child study clinic staff. He was enrolled in a structured normal preschool program for one year where considerable progress was made. The following year he was enrolled in a special education program but was soon transferred to kindergarten and then first grade because of excellent progress. Currently he is in third grade and is doing very well academically. He still has some unusual behaviors, however, and discipline remains a problem.

Although local clinics serve the majority of referrals, some children require expertise available only in larger regional clinics. Local clinics as in this case can provide, in addition to initial evaluations, invaluable follow-up for children seen at regional clinics.

Case 3. A 7-year, 7-month old boy was referred to the University's Child Study Clinic by a local clinic because of delayed speech and language and learning difficulties. He was not felt to be mentally retarded, however, nor to have an emotional disturbance. Several hearing evaluations in the past had resulted in conflicting impressions. A hearing

evaluation 6 months prior to being seen at the University was reported within normal limits. Daily speech and language therapy and enrollment in a first grade classroom complemented by resource room assistance had resulted in little progress.

This boy proved difficult to examine. He was, however, found to be totally deaf in the right ear and to have a moderate hearing loss in the left ear. Psychological evaluation revealed normal intelligence in non-verbal areas. Placement in the Communications Classroom at the University for 1 week provided teachers with the opportunity to develop an appropriate educational program for him. Recommendations included a hearing aid, otolaryngology follow-up, an appropriate school program for the hard of hearing, intensive speech and language therapy, and public health nurse follow-up.

In this case, although initial diagnostic services were required from the regional clinic, appropriate treatment programs were available in the child's home community. Coordination of the necessary services was effectively carried out by the staff of the local clinic.

Discussion

Locally based child study clinics, as opposed to large regional clinics, have the advantage of providing the opportunity for truly effective implementation of therapeutic measures resulting from interdisciplinary evaluations in the child's own community. Local clinics also have the advantages of being more accessible to many families and being better able to provide appropriate follow-up than regional, geographically distant clinics. The establishment of local clinics, however, does not assure that these advantages will necessarily be realized.

Few professionals in non-metropolitan communities have had experience working as a member of an interdisciplinary team and many child study clinic staff initially had little experience working with developmentally disabled children. Although clinic staffs generally had an appreciation of the need for interdisciplinary function, they frequently had little practical knowledge of how to make the approach work. Hence, considerable time and effort were spent initially in helping clinic staffs learn the intricacies of interdisciplinary team processes as well as helping staffs upgrade their clinical skills.

Despite the problems in promoting the development of local child study clinics (Grass & Umansky, 1971), Washington State clinics have provided a valuable resource for developmentally disabled children and their families. In addition to providing services for these children and their families, the clinics provide a forum where clinic personnel and other community professionals can interface in solving some of the problems confronting the developmentally disabled. The local clinics, as well as stimulating a heightened awareness of the needs of the developmentally disabled in the communities served, have acted as important liaisons between the child and school, between schools and health departments, and between health departments and private physicians. Finally, local clinics have provided a valuable resource for regional clinics with respect to follow-up and program placement.

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Arise! Activate Dreams

GENERAL FEDERATION OF WOMEN'S CLUBS

1734 N Street, N.W., Washington, D.C. 20036 • Telephone 202-347-3168

Mrs. W. Ed Hamilton
Executive Secretary

March 14, 1977

The Honorable Jennings Randolph, Chairman
Sub-Committee on the Handicapped
Senate Committee on Human Resources
Senate Building
Washington, D. C. 20510

Dear Senator Randolph:

It is my understanding that the Sub-Committee on the Handicapped will have hearings on March 21 regarding legislation for persons with developmental disabilities.

If possible, I should like to appear before the Committee to tell about thousands of volunteers of the ten-million member General Federation of Women's Clubs who are now very much involved in programs and projects relating to developmental disabilities. Your committee members should be made aware of the assistance for training given to our volunteers by the University Affiliated Facilities, Research and Training Centers, the Regional Offices of the Department of Health, Education, and Welfare, and the Developmental Disabilities Office in Washington.

In September, a national training session for all of our State Presidents, Junior Directors, and national Executive Committee members was held in Washington. In October, 1976, a series of seven regional workshops for training the women was initiated. These were for the next level of our leadership -- the State Chairmen and Junior Chairmen.

Regions I, II, III
Developmental Disabilities Law Project
University of Maryland Law School, Baltimore

Region IV
U.A.F., University of Alabama Medical School, Birmingham

Region V
University of Wisconsin, U.A.F.
Regional Developmental Disabilities Information Center,
Madison

Region VI
Research and Training Center, Texas Tech, Lubbock

Region VII
University of Nebraska, U.A.F., Omaha

Region VIII
Regional Office, Special Projects

Regions IX and X
University of Oregon, Center on Human Development, Eugene

You will note that all of our workshops were held at U.A.F.'s or related facilities.

Since that time, a number of regional training sessions have been held in states for our regional and club presidents, as well as club members. Our members are working closely with the State Councils and others already involved in this work.

The volunteer segment of our population is a vital part of any program. Since the members of the General Federation of Women's Clubs have been actively involved in the social changes in this country for over 86 years, we want your Committee to know of our continued efforts on the national, state, and local levels for persons with developmental disabilities.

It would be appreciated if someone could call me at 202/347-3168, giving me the time and location of the Sub-Committee hearings. Thank you.

Sincerely,

Jewel B. Hamilton

Mrs. W. Ed Hamilton
Executive Secretary

GENERAL FEDERATION OF WOMEN'S CLUBS

1734 N Street, N.W., Washington, D.C. 20036 • Telephone 202-347-3168

Arbol Anthem Award

[redacted]

PROJECT SHARE

Objectives

1. Volunteering in school programs with the developmentally disabled--those with cerebral palsy, mental retardation, epilepsy, autism and learning disabilities.

2. Serving as advocates for individual and groups of the developmentally disabled.

3. Promoting adequate transportation avenues for the developmentally disabled

4. Promoting recreation and leisure-time activities for the developmentally disabled

Some Suggested Ways (only a few) of Implementing Objectives by Local Clubs

In each State, there is a Planning and Advisory Council for the developmentally disabled. Seek their suggestions and technical assistance.

Objective 1 - Volunteering in School Programs

1. Contact the local school superintendent, requesting his permission and suggestions on how club women may volunteer to work with the developmentally disabled students in the classrooms.

2. Meet with the building principals and teachers with whom the volunteers will be working. Some school systems have training for volunteers.

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Mrs. Henry Wagner, Jr.
1734 N Street, N.W.
Washington, D.C. 20036

Director of Junior Clubs
Mrs. Dan Schumacher
P.O. Box 871
Coolidge, Arizona 85228

GFWC, PROJECT SHARE, P. 2

1. Appoint a chairman in your club to co-ordinate the volunteers schedules with the volunteers and the classroom teachers. (It is very important that the volunteers be able to keep their schedule. It is most disappointing to a student if he is expecting someone to help him and this person doesn't show.)

4. For the Teacher and in the Classroom

Clerical: typing, duplicating, checking students' work

Instructional: Assist the teacher in facilitating the learning process, i. e. volunteer and assistant on a one-to-one basis in reading, math games, etc.

Physical Activities: Purposeful play, field trips

Health Services: Transportation to health clinics, clothing centers, help with basic needs

Serving as Liaison with School and Community Resources: the volunteers could develop a guide of community of community resources for the classroom teachers

Locating work opportunities for the students with developmentally disabilities who can participate in work activities

Audio-Visual: Taping lessons for individual students
Video-taping activities within the local community that have learning potential for the developmentally disabled students, i. e. "how bread is made" at the local bakery

Objective 2 - Advocates for individuals or groups of developmentally disabled

1. Many developmentally disabled people are now being released from institutions, because they do not belong there, to your communities.

We are asking that you help them to adjust to community life by:
a. Learning first who are the developmentally disabled, where they live in your community, and what are their needs with which you can help.
b. Helping to find suitable work, i. e. in sheltered workshops, community day centers. If you have no facilities where the developmentally disabled can work, begin the action to secure a facility for this purpose. Take it as a club project. (You might be able to use such a project for CIP.)

Examples of work that the developmentally disabled can do: repainting crates, packaging and folding work, letterwork painting, searching, salvaging of machines rejects, reconditioning of worn machinery and parts, etc.

You, as volunteers, can find contract work for the developmentally disabled in your community. See that the centers, where the DD work, get publicity; this will help them to get contracts.

c. Providing or helping to secure transportation to work for them or to agencies where they can receive needed services
d. Being a friend and shopping with them to purchase necessities or other items
e. Working out a budget for expenditures and savings with an individual or groups of DD who have just entered you community from an institution
f. Setting up a banking or savings account for these individuals if this is feasible
g. Helping in finding suitable housing, if needed. Many zoning laws restrict small group homes which are needed for DD. Check your zoning restrictions; DD are good neighbors.

2. For the DD in institutions, contact the administrator or the responsible agency to determine how your club members can be of service. Most institutions have a volunteer co-ordinator.

Objective 3 - Promoting adequate transportation for the developmentally disabled

1. Determine what kind of transportation is being used or can be used to transport the DD in your community.

2. If you have a transportation system, i. e. buses, subways, etc., are these facilities usable by DD? If not, contact the officials of the transportation system, requesting that these facilities be provided; work with the officials; sometimes transportation can be made accessible for DD by minor changes to the system.

3. If you live in a small community where there is no regular transportation system, work with your local and state officials to provide these resources for transporting DD to needed services and to work. Contact the local school superintendent to determine if a school bus or buses could be used at some time during the day for this purpose. Agencies, who serve DD, could work together with the school system to defray the cost. CLUB WOMEN COULD BE THE CATALYST in bringing the agencies together.

4. Check legislation to learn the limitations on accessible transportation for DD. If there are limitations, work with the legislators to have laws passed to remove them.

Objective 4 - Promoting recreation and leisure-time activities

In the communities or in the institutions, provide arts and crafts activities, such as painting, batik, dance, music, crafts of all kinds

Regional Meeting Agenda Many Families utilizing response resources

PROJECT SHARE
Pre-Board Briefing
General Federation of Women's Clubs
State Presidents, Jr. Directors, Exec. Committee, and Regional Presidents
FRIDAY, SEPTEMBER 10, 1976

Chinese Room, Mayflower Hotel
Washington, D. C.
9:00 a.m. - 4:00 p.m.

8:45	Registration
9:10	Welcome and Introductions - Mrs. W. Ed Hamilton, Chairman Community Education Division
	Greetings - Mrs. Harry Wagner, Jr., President, GFWC Mrs. Oscar C. Sowards, President Elect, GFWC & Liaison for Project Share
9:30	"Like Other People"
9:45	WHAT ARE DEVELOPMENTAL DISABILITIES - Ms Doris Haar, Director Research and Developmental, Developmental Disabilities Office, HEW
10:15	PROJECT SHARE - Mrs. Hamilton
10:30	Break
10:45	ROLE OF THE STATE COUNCIL FOR THE DEVELOPMENTALLY DISABLED - One of the Ways to Seek Help - Karen Lapidus, Executive Director Maryland Council for the Developmentally Disabled
11:15	INFORMATION AND EXCHANGE SESSIONS

Advocacy

Presiding: Mrs. Thos. Donahue III
Leader: Mrs. Mary Ackerly
Consultant: Dr. Elizabeth Boggs

School Volunteers

Presiding: Mrs. John J. Barbour
Leader: Mrs. Harriet Naylor
Consultant: Mrs. Marilyn Hyde

12:15 Lunch on Your Own

1:45 Pam Powell, The White House, Director of Youth Affairs

2:00 INFORMATION AND EXCHANGE SESSIONS

Transportation

Presiding: Mrs. Don McGiffin
Leader: Dr. Ira Laster
Consultant: E. Clarke Ross

Leisure Time and Recreation

Presiding: Mrs. Kenneth Perkins
Leader: Mrs. Marjorie Kirkland
Consultant: Paul Marchand

3:00 NEXT STEPS

Questions and Answers
Feedback & Evaluations
Announcements

3:45 "I'm Not What You See"

Senator STAFFORD. Now, the Chair will announce that this committee will be in recess until the call of the Chairman.

[Whereupon, at 11:30 a.m., the subcommittee was adjourned.]